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Smart mobile and wearable technology for support and monitoring in dementia rehabilitation

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Smart mobile and wearable technology for support and monitoring in dementia rehabilitation

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Abstract

Healthcare systems are undergoing a paradigm shift driven by growing demands on resources due in part to an ageing population and by opportunities presented by rapidly advancing technology. The vision for future healthcare is a decentralised model supported by technology and encapsulated by the P4 healthcare framework of predictive, preventative, personalised and participatory care, a vision yet to be realised in practice.

This PhD project addresses the complex task of designing future healthcare systems by bringing together engineering design, technology and health sciences, focusing on dementia care as a representative case example and important challenge for society. Specifically, this work examines the potential role of mobile and wearable technology in dementia care for supporting both patient quality of life and care practices, fulfilling three main objectives: First, opportunities for personal mobile and wearable technology to meet needs of the dementia care network are identified through a field study at a dementia clinic and review of literature. Second, a novel technological solution is developed to perform the dual purpose of providing adaptable, personalised support for people with dementia in everyday life and generating continuous, objective measures of mobility and activity for behavioural monitoring. Third, the technological solution is implemented in a real-life setting among people with early-stage dementia in six eight-week case studies to evaluate its feasibility for augmenting rehabilitation interventions in practice.

Findings show the potential for pervasive technologies to address functional, psychosocial and safety needs among people in the early stages of dementia, for example through support with remembering tasks, appointments or information, recalling faces/names, navigating home independently, facilitating communication and motivating physical activity – all of which contribute to overall function in everyday life and social engagement. Familiarity and personalisation are highlighted as key factors for user acceptance. Lifespace mobility and activity features calculated from location, activity and step-count data were able to reveal patterns and trends in behaviour, potentially enabling timely and targeted intervention and collaborative care.

A core contribution of this work is the application of mobile/wearable technology and the data this generates in dementia rehabilitation using an engineering systems perspective to improve patient quality of life and advance personalised, participatory, predictive and preventative (P4) healthcare. This work offers a set of analytical tools for understanding human behaviour to inform the design

of engineering systems, or for monitoring in a range healthcare applications including for active ageing, lifestyle-related illnesses, rehabilitation or mental health. Furthermore, this work presents knowledge regarding available tools to support everyday life among people with dementia and factors influencing their acceptance, and provides evidence describing the feasibility of using personal mobile and wearable devices for goal-oriented dementia rehabilitation. Through these contributions and in answering related research questions, this PhD projects advances progress towards realising envisioned healthcare systems of the future.

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Articles included as appendices or otherwise referred to in this thesis:

Appendix A	**Thorpe, J.R.**, Patou F., Forchhammer, B.H., & Maier, A. (Submitted 2018). Designing predictive, preventative, personalised and participatory (P4) healthcare systems: a review of status and open challenges. Submitted to *International Journal of Design*, 12/06/2018.
Appendix B	**Thorpe, J.R.**, Rønn-Andersen, K., Bien, P., Özkil, A.G., Forchhammer, B.H., & Maier, A. (2016). Pervasive assistive technology for people with dementia: a user-centred design case. *Healthcare Technology Letters*, 3(4), 297 – 302.
Not in thesis	**Thorpe, J.R.**, Forchhammer, B. H., & Maier, A.M. (2016). Needs Elicitation for Novel Pervasive Healthcare Technology. In *14th International Design Conference - Design 2016 (pp. 1947-1956).* Design Society.

Chapter 1

INTRODUCTION

1.1 Motivation and aim

The future holds great challenges for our healthcare systems. A demographic shift towards older populations is causing a rise in prevalence of age-related chronic illnesses, and reducing the relative size of the workforce available to provide care [2], [3]. To cope with ageing populations, policy makers have called for solutions that ease the pressure on health care systems and support healthy ageing with a focus on function in everyday life and social or community engagement [2]. Similar demands across the healthcare spectrum, confluent with rapid technological advancement of the last decades, are fuelling a paradigm shift in healthcare [4], [5]. We are moving from a centralised care delivery model focused on diagnosing and curing disease towards a decentralised (or distributed) model focused on maintaining and enhancing health and wellbeing. In this vision for future healthcare systems, care recipients are not limited to diseased patients but include all people. Care activities move beyond treating illness to encompass a broad range of preventative strategies and health promotional activities, carried out collaboratively between care providers and recipients. Care delivery is not restricted to discrete events at hospitals and clinics but permeates our home and community environments throughout our everyday lives. This increased complexity underscores the need for an engineering systems perspectives in healthcare design [6]–[9].

Technology plays a pivotal role in realising this future healthcare vision. Technological progress in leaps and bounds has brought about ubiquitous sensing technologies for gathering data remotely, analytical tools for deriving insights from this data, and information and communication technologies for sharing these insights and connecting care recipients with providers [5], [10]–[12]. Technology has been applied in healthcare towards broadening access to care, reducing costs, and/or improving care quality. Designing technology-supported healthcare systems of the future is no trivial task. A diverse population of users includes those limited by their condition in their ability to use technology or express their needs. Rapid technological development has led to vast, fragmented health technologies that quickly become outdated. These rapid development cycles are one way in which technological research and development contrasts with research traditions of health and medical sciences, a disconnect that can hinder necessary cross-disciplinarity.

This PhD thesis addresses the design of technology-supported healthcare systems through the lens of dementia care. Dementia exemplifies the concerns raised by an ageing population. Flagged as a public health priority by the World Health Organisation, dementia is expected to increase in prevalence from 47 million people in 2015 to 132 million by 2050 with alarming economic impact that could overwhelm health and social services [13]. This project looks specifically at the group of individuals in the early stages of dementia, including those who live in the community and suffer from mild-to-moderate cognitive impairment. The earlier in the care process, the greater the potential for burden reduction through promoting independence and preventing decline. Important components of healthcare systems for complex illnesses such as dementia include function, community engagement, and patient empowerment [14]. Function here refers to independence in an everyday life context, i.e. through the ability to carry out activities of daily living (ADL) such as washing and dressing, shopping, cooking, cleaning, or walking the dog. Community engagement includes promoting physical, mental and social activity as imperative to caring for elderly people living in the community. Patient empowerment refers to giving patients ownership of their condition and the tools and resources necessary to take responsibility for managing it.

There is boundless potential for technology in responding to the dementia burden. This project focusses specifically on opportunities presented by mobile and wearable technology. Products such as smartphones, tablets and connected wearables could provide pervasive support that reaches many people throughout their everyday lives. Their communication and sensing capabilities present exciting opportunities to gather rich datasets and share insights derived from these among the care network. As smartphones and wearables become ever more popular and ubiquitous, they will also be increasingly familiar to future users, making them easier to learn to use and less stigmatised than traditional assistive devices. Furthermore, smart technology provides a modular platform that can be linked to different applications and sensors for varied support and monitoring capabilities. This highly flexible and adaptable setup allows personalised solutions to fit users' individual needs that change over time as their condition progresses. The aim of this thesis can therefore be stated as follows:

To examine the role of smart mobile and wearable technology in healthcare systems for supporting both patient quality of life and care practices, specifically within the context of dementia.

This aim is achieved by bringing together three core domains, filling a niche at their intersection:

- The engineering design field brings systems approaches with the holistic viewpoint necessary to deal with the complex, sociotechnical nature of healthcare systems.

- Health sciences bring the medical and clinical knowledgebase on disease symptoms, trajectories and treatment methods necessary to understand needs and work processes.
- Technology sciences bring new devices, sensors and analytical tools that offer revolutionary capabilities for generating and sharing health-related information on a vast scale.

Several limitations are also evident across the above fields. The engineering design field is limited in approaches geared towards integrating new technologies and the data these yield into future healthcare systems. Health technology is highly fragmented and faces challenges regarding user acceptance and adoption. Current approaches to clinical treatment of dementia are also limited: not everyone responds to pharmacological treatment, it has an effect for a limited period, and to-date, cannot cure dementia. Non-pharmacological approaches have shown promise for maintaining independence and quality of life, however further evidence is needed [15], and these methods require considerable input from healthcare professionals in providing support and assessing patient status on a regular basis. These limitations within each domain are addressed through their synthesis in this research. The P4 framework of *predictive, preventative, personalised and participatory healthcare* transverses the core domains discussed above and is applied to guide this work by defining an ultimate vision for future healthcare systems. This PhD project focuses on the following avenues for contribution and impact:

- *Leveraging available technology for support in everyday life:* This project leverages common tools (devices and applications) in place of developing specialised tools from-scratch. Familiarity of widely used tools and the personalisation afforded by an adaptable approach to their selection from a wider range both support user acceptance. Through identifying and testing existing tools, this work therefore contributes with knowledge about available resources that could provide personalised, adaptable support in everyday life to people with dementia. It also provides case-based insights about acceptance of the latest mobile and wearable technologies among elderly and cognitively impaired users and describes selected factors that might enhance acceptance.
- *Development of a behavioural monitoring solution:* A collection of algorithms is compiled, adapted and developed further to create a solution for measuring activity and mobility behaviour from sensor data generated by personal mobile and wearable devices (e.g. smartphones). In doing so, this work contributes with tools for deriving insights from data that tell us about users' behaviour and how this changes over time. This could aid the design

of products and services better suited to users' needs and lifestyles. Within a healthcare context, this provides continuous, objective information about patient status or treatment outcomes in between interactions with healthcare providers. Such information can be shared among the care network to facilitate collaborative care decisions and to inform timely and targeted intervention strategies.

- *Integration of technology-based support and monitoring into clinical practice:* The support and monitoring solutions described above are put to test in a real-life context among the target population group (people with early-stage dementia and their caregivers) in pilot testing and a series of longitudinal case studies. This provides novel evidence showing the potential for mobile and wearable technology to perform both support and assessment or monitoring roles in rehabilitation interventions for dementia. The solution benefits from the pervasiveness of the technology upon which it is built to provide support that is accessible to many throughout their daily lives and to offer rich datasets necessary for advancing predictive, preventative, personalised and participatory (P4) healthcare.

The following section lays out the research questions and objectives defined for the fulfilment of the project aim and for offering contributions towards described engineering design, technological and clinical challenges and ultimate P4 healthcare vision.

1.2 Research questions and objectives

In light of the project scope and aim, the following main and overarching research question is defined:

> *How can healthcare systems incorporate mobile/wearable technology to fulfil both support and monitoring roles to improve patient quality of life and to inform care?*

This research question is addressed specifically within the context of dementia, and is explored through four sub-questions:

RQ 1. Which needs of the dementia care network might be supported by smart mobile/wearable technology?

RQ 2. How can smart mobile/wearable technology fulfil the identified needs of the dementia care network?

RQ 3. How can data generated by mobile/wearable sensors inform dementia care approaches?

RQ 4. How can mobile/wearable technology, through fulfilling support and monitoring roles, improve quality of life among people with dementia?

Three objectives are laid out to answer these research questions:

1. Describe current dementia care practices and a proposed scenario incorporating technology (RQ 1 & 2)
2. Create a technological solution by combining and adapting existing devices, sensors, applications (apps) and algorithms to support dementia care (RQ 2)
3. Evaluate through clinical implementation of the technological solution its feasibility in terms of supporting patient quality of life and informing care (RQ 3 & 4)

The approach employed to fulfil these objectives is described in the following section.

1.3 Research approach

The overall research approach taken can be described according to the Design Research Methodology [16], including four stages. In a *research clarification* stage, literature is studied to orientate the project across engineering design, health technology and clinical domains to refine the approach for further project stages. This is followed by a *descriptive study I* in which current and proposed scenarios are explored and described (explore), a *prescriptive study* in which a technological setup is developed towards realising the proposed scenario (create), and a *descriptive study II* in which the prescribed technological setup is evaluated (evaluate). The descriptive study I, prescriptive study, and descriptive study II stages cover the fulfilment of project objectives 1, 2 and 3 respectively. Figure 1 provides an overview of how the chapters are aligned with the objectives and methodological steps.

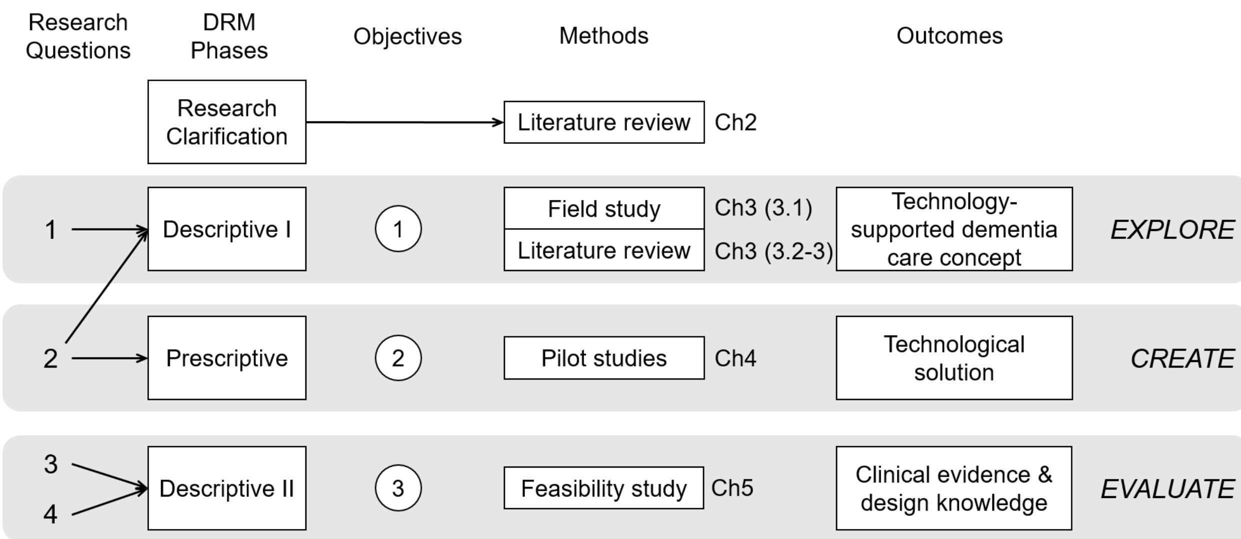


Figure 1. Thesis structure mapping research questions and objectives to the Design Research Methodology (DRM) steps, methods and outcomes, and indicating associated chapters.

The project was carried out in collaboration with the dementia and memory clinic at Rigshospitalet-Glostrup in Denmark. This collaboration facilitated the involvement of multiple actors from the dementia care network, including various healthcare professionals, people with dementia and their family caregivers throughout all project stages. Data collection was supported by the clinic, who recruited dementia patients and their caregivers to participate in research activities and provided clinical data for these participants, including cognitive impairment assessment scores. The data used in this research consists primarily of sensor data from mobile and wearable devices. This was collected through pilot tests with healthy volunteers and in case studies with dementia patients recruited through the clinic. The sensor data was used to develop a behavioural monitoring solution (Chapter 4) and for its evaluation (Chapter 5). The datasets and quantitative and qualitative analysis methods employed for each project objective are as follows and described in more detail the respective corresponding chapters:

Objective 1, *to describe current dementia care practices and a proposed scenario incorporating technology:* This objective is completed using data collected through a field study and review of literature. A field study is conducted at the dementia and memory clinic to collect data through interviews and observation. This is analysed qualitatively to describe current care practices and identify needs of the dementia care network. Literature on assistive technology for dementia and on sensor-based behavioural measurement is reviewed to validate and extend the set of user needs and to identify opportunities for technology to meet these (described in Chapter 3).

Objective 2, *create a technological solution by combining and adapting existing devices, sensors, apps and algorithms to support dementia care:* Data for this objective is collected from smartphone and smartwatch sensors. Pilot studies with healthy volunteers were used to collect sensor data for algorithm development using signal analysis and machine-learning techniques. Pilot studies were also employed to test usability and usefulness of devices and applications among participants with dementia. These pilot tests are described in articles [17] and [18] respectively resulting from research conducted in this thesis, and in Chapter 4.

Objective 3, *evaluate through clinical implementation of the technological solution its feasibility in terms of supporting patient quality of life and informing care*. This is completed as a feasibility study in the form of six case studies involving people with early-stage dementia and their caregivers. The approach for this study includes elements from the Copenhagen Center for Health Technology CACHET Unified Methodology for Assessment of Clinical Feasibility [19], including evaluation of technology adherence, usefulness and clinical utility and is adapted to fit the technological concept and study aims. Data is collected from mobile and wearable devices used by participants over eight weeks, including sensor data, device logs and mobile self-reports. Other data sources include clinical assessments and interviews. Statistical analysis including machine learning techniques and visual assessment methods are applied to extract relevant features, evaluate clinical utility, and compare participants' self-reports with sensor-based measures. Qualitative analysis methods are applied to interview data to evaluate user acceptance of smartphones/smartwatches for support in everyday life. The feasibility study implementation and analyses are described in an article resulting from this thesis [20] and Chapter 5.

1.4 Thesis outline

The remainder of this thesis is structured as follows. Work resulting from this thesis project already published or under review form the basis for selected chapters as referenced:

Chapter 2 provides a literature background on project domains including within engineering design, technology and health sciences to place the research across these. The P4 healthcare framework of predictive, preventative, personalised and participatory care is introduced to frame the vision for future healthcare systems used in this thesis across the core research fields. The P4 framework is applied to review literature on technology-based interventions for dementia to pinpoint key directions to advance P4 healthcare, thus guiding the research in this thesis. The main outcome of this chapter is the identification of gaps and limitations in literature that define the research directions followed in consequent chapters.

Chapter 3 presents the *explore* phase fulfilling project objective 1 and includes three sections. Section 3.1 documents a field study carried out at the start of the PhD project to understand the clinical problem, current dementia care system and needs of actors within this. Section 3.2 presents a review of literature on assistive technology for dementia to further investigate which needs these target and how these might be fulfilled using available smart mobile and wearable technology. Section 3.3 documents a review of literature on sensor-based behavioural measures and relates these to current dementia care processes to describe a proposed scenario. This section is a peer-reviewed conference paper and is included as published in [21]. The outcome of this chapter is a description of the requirements for a technological setup incorporating support and monitoring functionality.

Chapter 4 presents the *create* phase fulfilling project objective 2 and includes two sections. Section 4.1 briefly describes preliminary development steps taken to select devices and applications, and test their usability and usefulness as support among people with dementia. The section is based on a peer-reviewed and published journal article [18]. Section 4.2 documents the development of a behavioural monitoring solution using location and activity data from smartphones and smartwatches. This section is a journal article published as preprint while under peer-review at the time of thesis submission [17]. The outcome of this chapter is a technological solution to fulfil support and monitoring purposes in dementia rehabilitation.

Chapter 5 presents the *evaluate* phase fulfilling project objective 3 and includes two sections. The main section (5.2) documents a feasibility study carried out among a group of people with dementia and their caregivers to evaluate the technology-supported care concept developed in previous chapters. This is a journal article published as preprint while under peer-review at the time of thesis submission [20]. Preceding this in 5.1 are notes on clinical perspectives on the relevance of sensor-based behavioural measures, obtained through a workshop carried out during the development phase. The outcome of this chapter is the set of findings describing the feasibility of sensor-based behavioural monitoring using smartphones and smartwatches among people with dementia, the relevance of resulting mobility and activity measures for clinical practice, the potential benefits of these same devices as support in everyday life, and their acceptance among target users.

Chapter 6 discusses the results and contributions of this thesis in relation to the research questions outlined in section 1.2, infers directions for future work, and provides concluding reflections.

Chapter 2

DOMAIN BACKGROUND

The aim of this chapter is to position research undertaken in this PhD project within the three domains of engineering systems, technology, and health sciences and specifically across healthcare system design, health technology, and dementia care and rehabilitation. This chapter summarises and synthesises contributions from these domains that have informed this research, identifies knowledge gaps, and uses these to further define the project scope and focus. The P4 healthcare framework of predictive, preventative personalised and participatory care intersects all three domains and is applied to frame the project's overall vision.

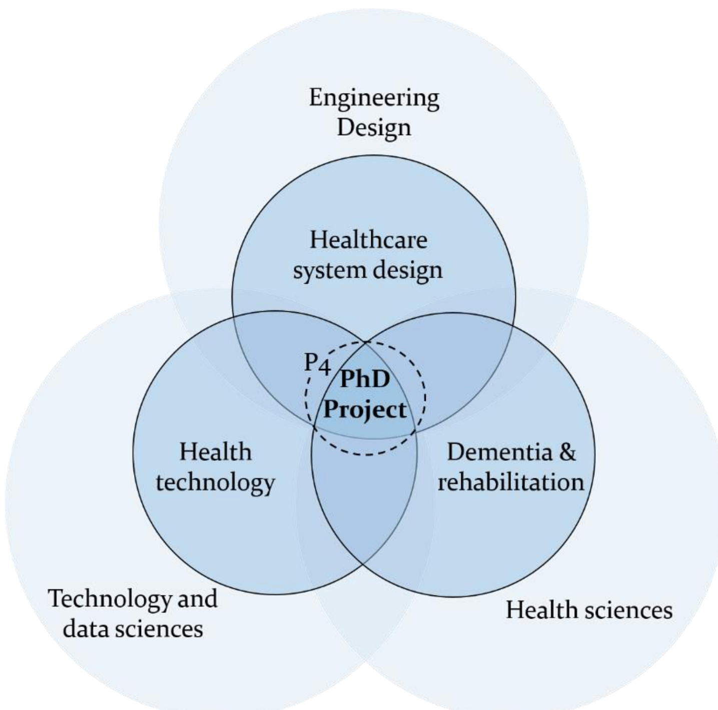


Figure 2. Venn diagram showing domains integral to the research conducted in this PhD project. The P4 framework intersects engineering systems, technology and health sciences, framing the overall vision for future healthcare systems in this thesis.

2.1 Healthcare system design

"Every intervention, from the simplest to the most complex, has an effect on the overall system, and the overall system has an effect on every intervention." [22]

Healthcare is an archetypal engineering system. De Weck's defining characteristics of engineering systems as "*a high degree of technical complexity, social intricacy, and elaborate processes, aimed at fulfilling important functions in society*" [23] will apply to healthcare in future even more so than today. This work is therefore guided by literature that recognises healthcare challenges as engineering system design challenges. This includes work that describes healthcare as an engineering system, applies systems approaches to solving healthcare problems, and contributes with engineering design methods and tools of particular relevance for the healthcare context underlying this thesis.

Rouse has described healthcare as a *complex adaptive system* with the following characteristics: it is dynamic, has multiple control points, shows emergent behaviour, and is composed of independent, intelligent agents whose goals and behaviours are likely to conflict [24]. The structure of healthcare systems has also been described. A report on systems thinking in healthcare by the World Health Organisation (WHO) presents six subsystems including governance, the workforce, service delivery, medical technologies, information and financing, all centred around people [22]. Rouse and Serban describe four interdependent levels of the *enterprise of healthcare delivery* as ecosystem (society), system structure (organisations), delivery operations (processes), and clinical practice (people)[25]. Nelson et al. [26] use the term *clinical microsystems* to describe healthcare using a systems perspective, defined as the smallest units most directly involved in delivering care to a patient and that form larger healthcare systems. This concept has been applied to improving care quality on the basis that the quality of the wider care system is determined by quality on the microsystem level [27]. While system descriptions vary in detail, these show that the multiple actors in healthcare systems relate through shared activities and information transfer, and that even on the smallest scale these actors typically include at least care recipients (patients) and providers (healthcare professionals).

Works referenced above are part of a growing body demonstrating the value of a systems approach in healthcare and offering guidelines for its application. Clarkson and colleagues investigate in detail the potential for systems approaches to improve patient safety in the UK [28]. The potential for improvement more broadly across healthcare goals is underlined in a report on systems thinking for health system strengthening by the WHO [22]. The report provides 10 steps for applying systems thinking to design and evaluation of healthcare interventions. The design phase involves convening stakeholders to collaboratively brainstorm, conceptualise and adapt/redesign an intervention. The evaluation phase includes selecting indicators, methods and a design, developing a plan, setting a budget and sourcing funding. A recent (2017) report by the UK Royal Academy of Engineering, the Royal College of Physicians and the Academy of Medical Sciences documents a systems approach to healthcare design [6]. The report describes four perspectives: *people*, *systems*, *design* and *risk*; and uses a set of guiding questions to translates these into a framework for design and improvement of healthcare systems. Four phases for implementing the approach are defined as *understand*, *design*, *deliver* and *sustain*. The approach is exemplified using a number of case studies, including the development of a model for care for the elderly with complex needs.

Besides these overarching models, characteristics and frameworks, a collection of concepts and tools from the engineering design field is available to support the design of healthcare systems. Of specific relevance for dementia care and the work carried out in this thesis are inclusive design and participatory design, which are closely related and fall under the umbrella concept of user-centred design. The inclusive design premise is to design artefacts suitable for diverse users taking into account their abilities [29], [30]. This is highly relevant for design in healthcare generally given the spectrum of potential limitations imposed on patients by their condition, and particularly for dementia care in which users are affected by a variety of age-related limitations as well as cognitive impairment. Participatory design – which refers to the involvement of stakeholders in the design process - is both a concept in its own right and a means towards achieving the goals of inclusive design. Involving patients in the design process can be encumbered by limitations posed by their condition. Researchers in participatory design have made valuable progress towards addressing these challenges, including for people with cognitive impairment [31].

One area in which the engineering design field currently falls short is the integration of new sources of data – as well as the tools required for its analysis and the insights these generate - into healthcare systems. The status of data use in healthcare systems lags far behind today's actual technical capabilities. Current use of digital data in healthcare resembles automation of clinical practice that tends to interrupt clinical workflow and interactions with patients rather than supporting these [32]. A transformation is needed from clinic-based capture of patient data towards more multimodal signals gathered automatically across system boundaries. As the availability of actionable health data from sensor-rich personal devices increases, so are design approaches needed to integrate this into healthcare systems. Here we turn to technology sciences, where significant contributions have been made over the last decades towards the changing role of technology in healthcare, discussed in the following section.

2.2 Health technology

"Pervasive healthcare addresses those technologies and concepts that integrate healthcare more seamlessly to our everyday life, wherever we are." [33]

The last decades have seen prolific research on the application of information and communication technologies in healthcare, reflected in the emergence of new fields such as telehealth, eHealth, mobile health (mHealth), pervasive healthcare or ubiquitous health (uHealth) and personal health technology. Two of the earliest, telehealth and eHealth, describe using technology to deliver healthcare services remotely and using electronic data to support healthcare processes respectively. With advances in smart, mobile and wearable devices, mobile health and ultimately pervasive healthcare have merged and extended these purposes [10], [34], [35]. The umbrella term personal health technology refers generally to the use of personal devices for health self-management, largely overlapping mobile and pervasive healthcare, and fuelled by the quantified-self movement [36]. Pervasive healthcare also connects directly to concurrently developing fields beyond the healthcare domain, including ubiquitous computing and internet-of-things [37]. These fields offer various descriptions of health technology systems or architectures and support for their design.

A four-step process has been described for the *internet-of-things ecosystem* that is applicable to health technology: data acquisition from sensors, creation of information through software processing, deriving meaning from information through visualisation, and a final action-taking step [37]. Focusing on healthcare, Bardram and colleagues have published definitive work on pervasive healthcare [38], [39] and offer contributions in the form of design guidelines and case examples. The double-loop model for designing personal healthcare applications relates the technology to both the care recipient and provider [40]. A more detailed representation is provided in the *personal health technology design space,* intended to guide designers of health technology in making informed decisions. This includes 10 dimensions across four categories: intervention, data processing, feedback, and regulatory issues. Each dimension is represented as a spectrum between two opposing choices, such that the designer can determine a position between these and map a path across the design space.

The process, model and design space described in literature [37], [40], [41] provide high-level descriptions. When it comes to filling in the details, however, data acquisition is partly determined by available sensors and infrastructures, and actions taken are largely informed by the specific healthcare domain (e.g. dementia care) including clinical knowledge dealt with in the next section. The steps between acquiring data and taking action - deriving meaning from data – form a black box from the pervasive healthcare perspective that requires further input from related, data-science oriented fields. Broadly speaking, a goal of the data processing black box can be interpreted as using sensor data to measure and understand human behaviour, for which foundational work comes from computer sciences [42]–[45].

Within the context of dementia care, the focus for this project can be narrowed to information about behaviour indicative of the health of elderly people with cognitive impairment. In line with healthcare goals outlined earlier, function (i.e. performing daily life activities) and engagement are further pinpointed as important outcomes to measure. This leads us to two aspects of behaviour, mobility and activity, which can be described using mobile sensor data, presenting an interesting avenue for behavioural monitoring among people with dementia to be explored further in this thesis. A review of literature describing techniques for extracting meaningful information regarding mobility and activity from sensor data is provided in section 3.3 (published in [21]). Core examples built upon in this thesis demonstrate the use of mobile sensor data, including location, step count and/or physical activity signals, to measure mobility and/or activity for health monitoring among cognitively impaired and mental health patients [46]–[49].

While the role of technology including mobile devices, sensors, data and analytical tools in healthcare is expanding at an astounding pace [10], [35], acceptance and adoption of health technology solutions cannot be taken for granted. As we move towards a future where those who stand to benefit most from mobile health are elderly populations (e.g. for managing multiple chronic illnesses, circumventing travel to the centralised clinics), the more important it is becoming to understand needs and limitations of the elderly population in relation to the technologies upon which mobile health is built [50]. The value of engineering design approaches such as user-centred design for fitting designed technologies to their intended users is touched on earlier. Furthermore, placing the plethora of emerging mobile devices, sensors, data and analytical tools in wider health systems requires consideration for implementation in clinical practice. Clinical knowledge is necessary to guide decisions about what to measure or what actions to take given certain information. The next section shifts perspective to the patient and healthcare professional on either side of the health technology.

2.3 Clinical background on dementia and rehabilitation

"Interventions that aim to reduce functional disability by targeting activity and participation, drawing on retained strengths to support adaptive behaviour, are typically described as forms of rehabilitation." [51]

The clinical condition dealt with in this project is mild to moderate dementia. In 2015, shortly after this project started, the global prevalence of dementia was reported at 46.8 million people and projected to almost double every 20 years [52]. Around 89.000 people in Denmark suffer from dementia, costing ~24 billion Danish kroner (~3.2 billion euro) annually before accounting for lost earnings and input from relatives. Dementia mainly affects people over 60 and rises exponentially in prevalence with age (from 1-2% for age group 60-64 up to 24-45% in age group 90+) [53], making dementia impact a major concern in relation to ageing populations [54].

Dementia is neither a natural consequence of old age nor a disease, but rather a condition associated with disease. As many as 200 diseases are known causes of dementia, of which by far the most common are Alzheimer's disease, vascular dementia, and a combination of those two. Of the registered dementia diagnoses in Denmark in 2016, over half were Alzheimer's disease (56,5%), with vascular dementia (14,4%) and vascular/Alzheimer's (12,6%) together making up a further quarter [55].

Dementia symptoms can be broadly categorised as cognitive and behavioural. The earliest and most common symptom tends to be impaired memory which can affect different memory. Even though the course of illness is highly individual, in the early phases of dementia typically episodic memory (specific to the individual and associated with time and place, e.g. details from a conversation with a friend at a café that morning) is affected. In later stages semantic memory (general knowledge, e.g. the names of famous people or places) and procedural memory (memory of how to carry out a practical process, e.g. to prepare food) is affected.

Besides and in relation to these memory impairments, other cognitive functions that can be impaired include attention, perception of time and space, problem solving and overview, language proficiency, and numeracy. Behavioural and psychiatric symptoms include depression and lack of initiative, apathy, angst/anxiety, aggression and agitation, delusion, and hallucinations. All of these symptoms – both cognitive and behavioural – have direct meaning for everyday life among people with dementia: from performing tasks around the home, to getting around in the community, socialising with friends and family, or maintaining hobbies and interests. This substantiates the growing emphasis on function and engagement as a priority for dementia care [13], [14].

Clinical treatment of dementia today includes drug therapy supplemented by access to educational resources and community support for people with dementia and their caregivers. There is currently no cure for most dementias (including Alzheimer's and vascular dementia), and although drug therapy can reduce symptoms, it is only effective for a limited period and not all people respond to treatment. Non-pharmacological approaches to treatment are not systematically implemented in clinical practice today, however are gaining attention [15], [56]. One such approach to dementia care is through rehabilitation, which has been defined as "*an educational, problem-solving process that focuses on activity limitations and aims to optimize patient social participation and well-being, and so reduce stress on carer/family*" [57].

Within the context of dementia, rehabilitation aims to reduce the impact that a person's cognitive impairment has on their quality of life by helping them to achieve individual goals related to functional and behavioural problems in a real-life context. Strategies for achieving goals are devised and implemented collaboratively between patients, their family caregivers, and healthcare professionals. It is by definition a highly personalised and participatory approach [15], [58], [59]. In a description of rehabilitation interventions, Wade presents three considerations including *process*, *structure* and *outcomes* [57]. The *process* is iterative and includes steps for problem definition, assessment, goal setting, intervention and evaluation to determine whether further iterations are necessary. Two core elements of the intervention step include provision of support and collection of further data for ongoing evaluation to inform future iterations. *Structure* refers to the resources needed to implement rehabilitation, including technological tools. *Outcomes* refers to overall goals, generalised as maximising social participation of the patient and minimising distress to them and their family.

The application of cognitive rehabilitation among people with dementia has been documented by Clare and colleagues in the IDEAL (Improving the experience of Dementia and Enhancing Active Life) and GREAT (Goal-oriented cognitive rehabilitation in early-stage dementia) studies. These studies have shown promise for supporting the needs of people with dementia, and are extending the body of evidence surrounding non-pharmacological approaches to dementia care. Another important contribution from these studies has been to provide further detail on the role of the therapist in terms of activities within the above rehabilitation process [51]. Besides goal setting, these include identifying, devising and/or reviewing strategies for: goal attainment, reducing stress and anxiety, monitoring and increasing activity, maintaining or improving attention, and memory support.

In this thesis, the role of mobile technology is examined as part of the *structure* for the above rehabilitation model to support the patient in achieving the rehabilitation aims listed above. This has been investigated for other groups of neurological patients such as traumatic brain injury whereby patients use smartphones with calendar applications as a memory aid, showing that this approach was effective in reducing self-reported memory problems [60]. This PhD project employs a similar approach for dementia and investigates further smartphone-based support opportunities selected according to individual needs. In addition to support for patients, rehabilitation interventions include data collection for further evaluation – or monitoring [57]. Opportunities for monitoring among the elderly and cognitively impaired using pervasive technologies are expanding rapidly [61]. This thesis therefore further examines the role of technology for monitoring by investigating how mobile/wearable sensing capabilities might be leveraged to support collaborative devising and reviewing of rehabilitation strategies. The previous section has already pinpointed mobility and activity measurement as opportunities presented by mobile/wearable device sensors. These are examined in this thesis within the context of evaluating quality of life among the target group. This PhD project therefore merges and builds upon the roles of technology in both supporting patients to achieve goals for quality of life and evaluating consequent outcomes as a dual purpose within rehabilitation.

2.4 Summary and synthesis

This chapter has discussed several fields integral to the design of healthcare systems that offer design guidelines, enabling technologies, clinical knowledge and supporting evidence. However, each in isolation is unable to fully realise envisioned healthcare systems of the future. This thesis fills a niche role by synthesising input from healthcare systems design, health technology, and dementia rehabilitation to advance progress towards the design of technology-supported healthcare systems of the future. Use of personal mobile and wearable devices to provide support to people with dementia in rehabilitation interventions is sporadic, focuses on specific functionality, and tends to be addressed separately from monitoring. This work will therefore exploit identified opportunities to apply mobile/wearable technology for both support and monitoring in dementia care to promote quality of life among patients according to individual goals and inform proactive care approaches. An overview of the dementia care system within the scope of this thesis is depicted in Figure 3.

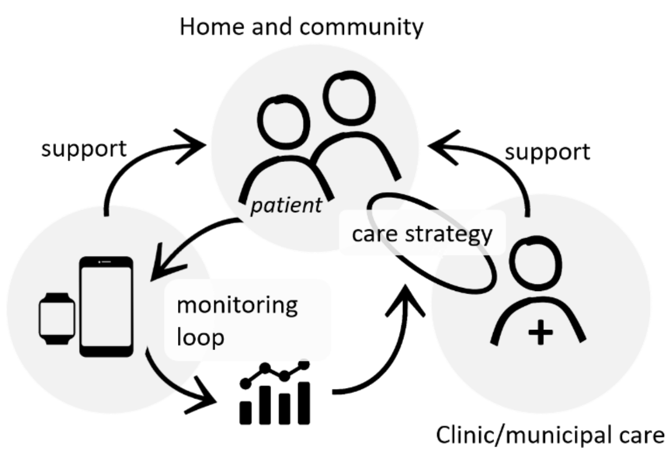


Figure 3. Dementia care system in focus for the PhD project. The patient and caregiver depicted in the centre with support provided from both healthcare professionals and technology, and a monitoring loop informing collaborative care.

A common, all-encompassing vision or goal for this multidisciplinary endeavour is offered by the P4 framework of predictive, preventative, personalised and participatory healthcare [4]. Convergent ideas surrounding the P4 healthcare concept transverse across engineering systems, technology and data sciences, health science and clinical practice [5], [62]–[64]. The following section applies the P4 healthcare framework to review literature on technology-based dementia interventions to direct research undertaken in this thesis.

2.5 The P4 healthcare framework

This section is based on the review article conducted as part of this PhD project entitled "Designing predictive, preventive, personalised and participatory (P4) healthcare systems: a literature review on status and open challenges", which is provided in Appendix A (submitted, under review). Several excerpts are included to summarise the methods and findings in relation to the aims of this chapter.

Today, healthcare systems are still predominantly tailored around the central, reactive, episodic and population-based (i.e. generic) care delivery model of conventional medicine [63]. For this model, the main objective is to react promptly to solicitations from symptomatic patients, i.e. to diagnose, treat and rapidly dismiss patients suffering an acute condition, or to provide episodic support for the chronically ill. The scientific and technological disruptions of the past two decades are driving a paradigm-shift in this model, with a trajectory set towards the advent of P4 medicine [62], [63], [65], [66]. Predictive, Preventative, Personalised and Participative (P4) medicine is deemed to emerge from the "confluence of a systems approach to medicine and from the digitalisation of medicine that creates the large data sets necessary to deal with the complexities of disease" [63]. In other words, P4 represents proactive healthcare delivery, more focused on wellness and on the implementation of anticipatory measures for predicting and preventing diseases or their adverse consequences. This vision contrasts with the main objectives and strongholds of our present healthcare systems: reactivity and short-term efficiency of episodic care delivery. Conceptualised after the completion of the Human Genome Project, and related breakthroughs in DNA sequencing technologies, the P4 vision relies as much on progress in the life sciences as on the capabilities offered by novel information and communication technologies including smartphones, smartwatches, wearables, data science and artificial intelligence. The concept of digitisation Hood et al. refer to is central in discussions on P4 framework and the future of healthcare: it evokes the digital capture of health-related information, but also the algorithms and devices on which the vision of personalised medicine rely [5], [12].

The aim of this review is to evaluate what progress has been made on the journey from conventional to P4 healthcare, and consequently, identify key areas to be developed. We systematically review literature with the following objectives:

- Review and analyse literature to relate healthcare technology based interventions (products, services and/or systems) to characteristics of conventional and P4 healthcare.
- Evaluate progress from conventional to P4 healthcare, identifying which elements are being achieved or lagging behind.
- Infer on the potential shortcomings of available engineering design frameworks, methods and tools in facilitating the emergence of P4 healthcare.

The literature search yielded over 700 results from which 30 articles were ultimately included in the analysis. The goal of the analysis was to map healthcare design examples described in the articles to a set of characteristics of conventional and of P4 healthcare. For conventional healthcare, these were *reactive*, *episodic/discrete*, *generic* and *centralised*, and for P4 healthcare, these were each of the "P's" (*preventative*, *predictive*, *personalised* and *participatory*) as well as *decentralised*.

The abridged results are shown in Table 1. These show that while decentralisation is well established, there is only limited preventative, personalised or participatory care, and an absence of predictive care approaches in the reviewed literature. The availability, acquisition and analysis of data could be inhibiting factors, particularly for prediction and personalisation, which are necessary for targeted prevention. Besides adequate data infrastructures, participatory care demands a considered approach to patient motivation, engagement and empowerment. We therefore recognise three key focus areas for the development of holistic frameworks to support the design of P4 healthcare systems:

- ***Data-centrality***: Systematic collection, aggregation and analysis of data from multiple sources is fundamental to P4 healthcare. Engineering design approaches aligned to the central role of data in healthcare systems are required to propel progress.
- ***Designing smarter systems***: Once data-related stumbling blocks are overcome, new knowledge and insights will become available regarding predicted trajectories/events and patient characteristics and needs. We need design approaches capable of applying this knowledge in the design of smarter interventions for more targeted prevention, comprehensive personalisation, and that adapt to change.
- ***Understanding human behaviour***: For care interventions to incite the desired action in care recipients for disease prevention and management, data-derived knowledge alone is insufficient. Engineering design frameworks should be heavily founded on cognitive and behavioural theories to support motivation and engagement, and foster collaboration.

Table 1. Abridged results relating articles to characteristics of conventional and P4 healthcare. Results are listed in descending, chronological order. Abbreviations: R = Reactive, E = episodic, G = generic, C = central, Pd = predictive, Pv = preventative, Ps = personalised.

#	Article	R	E	G	C	Pd	Pv	Ps	Pt	D
1	(Burton & O'Connell, 2018)						■	■	■	■
2	(Lindauer et al., 2017)	■	■	■						■
3	(Duggleby et al., 2017)			■				■		■
4	(Elfrink, Zuidema, Kunz, & Westerhof, 2017)							■	■	■
5	(Bahar-Fuchs et al., 2017)						■	■	■	■
6	(Lazarou et al., 2016)							■	■	■
7	(Jekel, Damian, Storf, Hausner, & Frölich, 2016)		■	■						■
8	(van de Weijer et al., 2016)						■	■		■
9	(Mirelman et al., 2016)						■	■	■	■
10	(van Knippenberg, de Vugt, Ponds, Myin-Germeys, & Verhey, 2016)	■		■				■	■	■
11	(Gaugler, Reese, & Tanler, 2016)		■					■	■	■
12	(Matthews et al., 2015)	■		■					■	■
13	(Tak, Zhang, Patel, & Hong, 2015)				■			■	■	
14	(Moreno, Elena Hernando, & Gomez, 2015)	■						■	■	■
15	(Baker, Huxley, Dennis, Islam, & Russell, 2015)			■					■	■
16	(Schaller et al., 2015)	■	■					■	■	■
17	(Cristancho-Lacroix et al., 2015)			■						■
18	(Boman, Lundberg, Starkhammar, & Nygård, 2014)	■		■			■			■
19	(Grindrod et al., 2014)		■		■		■	■	■	
20	(McKechnie, Barker, & Stott, 2014)		■	■					■	■
21	(Aloulou et al., 2013)	■			■			■		
22	(Blom, Bosmans, Cuijpers, Zarit, & Pot, 2013)		■	■			■		■	■
23	(García Vázquez, Moreno Martínez, Valero Duboy, & Gómez Oliva, 2012)							■		■
24	(F. J. M. M. Meiland et al., 2012)			■				■		■
25	(van Hoof, Kort, Rutten, & Duijnstee, 2011)	■					■	■		■
26	(Van Der Marck, Overeem, Klok, Bloem, & Munneke, 2011)	■		■						■
27	(Van Der Roest, Meiland, Jonker, & Droes, 2010)			■				■		■
28	(Hilbe, Schulc, Linder, & Them, 2010)			■	■		■			
29	(Mihailidis, Boger, Craig, & Hoey, 2008)							■		■
30	(Shoval et al., 2008)			■						■

Findings from this review article support the emphasis on leveraging data-derived insights generated by new technologies already touched on earlier in this chapter. We furthermore see a need to move beyond applying technology for remote delivery of care, towards addressing each of the characteristics of P4 healthcare, and in particular, enabling predictive and preventative care approaches capable of recognising trends and trajectories for timely intervention.

Chapter 2 conclusions

This chapter has presented core works from three domains central to this thesis: healthcare systems design as a part of engineering systems, health technology as a part of technology and data sciences, and dementia and rehabilitation as clinical topics within health sciences. Representations of healthcare systems, rehabilitation processes, and technology architectures are used to define a simplified representation of a technology-supported dementia care system investigated in this work. Identified gaps to be addressed by bringing together these respective domains include: limited design methods to support the integration of new technologies and the data these yield into future healthcare systems; fragmented health technology with low implementation in clinical practice and poor understanding of user acceptance and adoption among the elderly; and the limited use of new pervasive technologies such as mobile- and wearable technology to support dementia rehabilitation, e.g. by offering personalised support and the remote collection of large, objective datasets for monitoring progress. The P4 healthcare framework of predictive, preventive, personalised and participatory (P4) healthcare is recognised as a relevant, cross-disciplinary conceptual framework within which to define these research goals. A review of the current status and open challenges in designing P4 healthcare system supports the identified gaps as key directions for progress towards realising the vision for future healthcare systems.

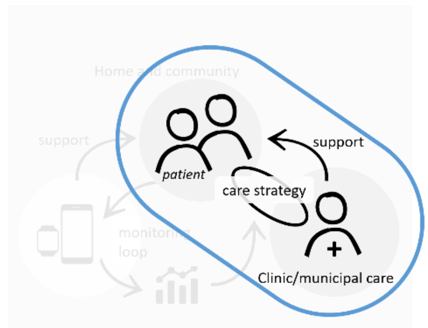
Chapter 3

EXPLORE

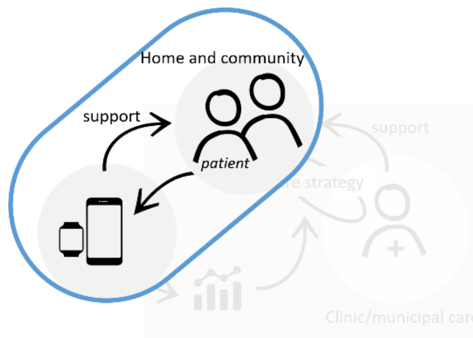
Objective 1: Describe current dementia care practices and a proposed scenario incorporating technology

Building on the findings from the preceding chapter, this chapter explores the dementia care system and potential roles of mobile and wearable technology within this. The chapter is divided into three sections each taking on different and complementary focal areas:

Section 3.1 documents a field study carried out at the dementia and memory clinic to learn about the current dementia care system, including actors' needs and the typical care process.



Section 3.2 explores how needs of people with dementia might be fulfilled by mobile/wearable devices. Literature on assistive technology for dementia is reviewed to identify target needs, which are matched to generic technological capabilities.



Section 3.3 explores sensor-based behavioural measurement opportunities from literature, and relates these to the dementia care process. This section is a conference paper published at the International Conference on Engineering Design (ICED17) [21].

Through these sections, we gain a more detailed understanding of how mobile and wearable technology might support dementia care practices. The chapter is concluded with a definition of the technical setup to be developed in the next chapter (objective 2).

3.1 Field study

A field study was carried out during the first months of the PhD project to orientate the researcher on the clinical topic and to gather information required for consequent project phases. The field study was carried out at the dementia and memory clinic at Rigshospitalet-Glostrup in Denmark. The first three weeks of the project were conducted at the clinic full time and the field study continued ad-hoc over a further nine month period. Primary objectives of the field study included:

1) Gain a deeper understanding of:
    a) the actors in the dementia care network and their primary roles
    b) a typical care process / map out a patient journey through the clinic
2) Gather information about the needs of the various actors in the care network, including regarding information and technology

In addition to these objectives, the orientation period at the clinic included training on dementia as the clinical problem in focus in this project (see Section 2.3). A map of the dementia care network is presented in the following section as outcome of the first field study objective, serving as background to the following sections, describing activities carried out and their outcomes.

3.1.1 The dementia care network

A typical care network for a person with dementia is depicted in Figure 4. This does not portray all actors across the wider healthcare system, but rather focuses on the clinic, home and municipal support (dementia consultant). For example, the patient’s general practitioner is not featured. Depending on their household/family situation, the caregiver typically provides most support to the patient and plays a primary role in communication with healthcare providers. At the clinic, the nurse acts as coordinator for the patient, liaising between other actors to share information and drive the care process. The specialist doctor’s primary role is evaluation and diagnosis. Neuropsychologists do not interact with all patients, but play a role in evaluation and diagnosis for those cases that necessitate neuropsychological evaluation. Dementia consultants are connected to the clinic as a whole and while they support both the patient and caregiver, it is the caregiver with whom they typically communicate most.

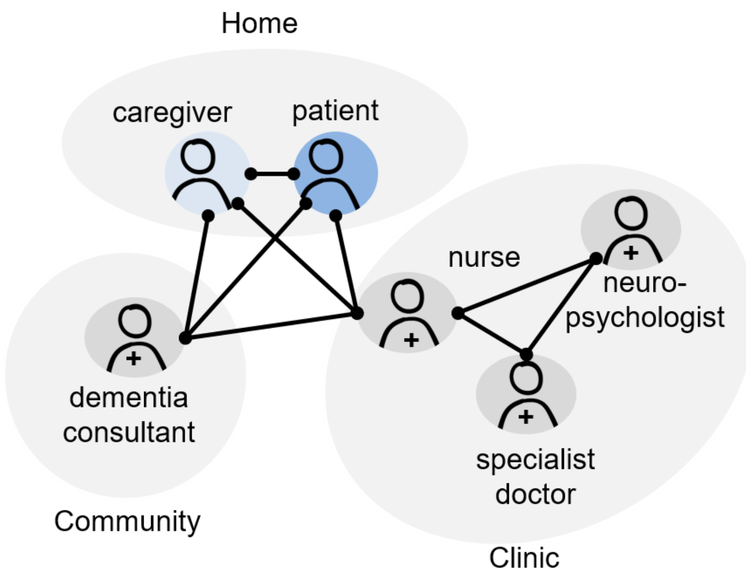


Figure 4. Dementia care network based on interactions with the clinic

3.1.2 Data collection activities

Data was documented in the form of field notes taken from observations and as recorded interviews with healthcare professionals. Observed activities including patient consultations, staff meetings, patient home visits, and family education workshops. These are summarised in Table 2 indicating which actors in the dementia care network are involved and described below. Appendix C lists the interviewees and observed patient-healthcare provider interactions in more detail.

Table 2. Summary of interviews and observation showing which actors are involved.

Activity	#	Description		Nurse	Doctor	NP	DC	Patient	CG
Interviews	6	Semi-structured interviews		2	1	1	2		
Patient Consultations	10	First or control	Assessment						
			Discussion						
	1	Information meeting							
	1	Neuropsychological exam							
Other activities	3	Staff meetings							
	2	Home visits							
	2	Caregiver education							
Abbreviations: Neuropsychologist (NP); Dementia Consultant (DC); Caregiver (CG)									

Interviewing healthcare professionals

Six semi-structured interviews of 15-45 minutes were conducted with healthcare professionals directly involved with examining, diagnosis and/or treatment of patients, including two nurses, a specialist doctor and a neuropsychologist, as well as two dementia coordinators from municipalities covered by the clinic. Interview questions covered the healthcare professionals' role in the care process (e.g. tasks and responsibilities, information needed to perform these, and challenges they face) and thoughts on support needs for people with dementia regarding both healthcare professionals and technology.

Observing patient consultations

Patients are typically accompanied by their caregiver for consultations which involve various healthcare professionals and activities. Examples of consultation types include:

- *First consultation*: clinical assessments followed by discussion about individual profile, symptoms and problems experienced in daily life to gather as much clinically relevant information as possible
- *Information meeting*: the patient and caregiver are informed about the diagnostic decision and a care plan is decided
- *Follow-up controls*: re-evaluate status and adjust treatment as required
- *Neuropsychological exam:* performed when there is some doubt about the severity or type of dementia. These are far more thorough than the assessment with the nurse, can last more than 2 hours and goes in-depth into specific functional domains of the brain.

For this thesis, first consultations were the primary focus, since it is here that most of the information is collected, thereby providing most insight into what kind of information healthcare professionals need as well as detailed descriptions from patients and their caregivers about their symptom-related difficulties in everyday life.

Shadowing dementia coordinators for patient home visits

Dementia coordinators visit people's homes when specifically requested by patients or caregivers. These allowed insight into what the dementia coordinator looks for in the everyday, home environment to evaluate the person's wellbeing. Visits to two homes were observed. The first involved a first meeting similar to initial consultations at the clinic. The patient was an 83 year old woman whose husband passed away a year earlier and who now lives with her adult daughter. The daughter requested the visit out of concern over her mother's poor memory and disorientation. The second visit involved a second meeting between the pair and dementia coordinator. This went into more detail about a specific problem that a couple was experiencing in their home life, with the goal of eliciting the help of the dementia coordinator in finding a solution. The patient was a 71 year-old man living with his wife. The wife is frustrated over constantly being asked about their schedule, initiated the meeting to discuss possible solutions. They are a socially and physically active couple who have difficulty with the impact his condition has on their lifestyle.

Observing educational workshops for caregivers

Resources offered to patients include caregiver educational workshops in which healthcare professionals present a specific topic, answer specific questions, and encourage discussion among attendees on their own impressions and experiences. Attendees include primary caregivers as well as other family members but patients themselves do not. Sessions cover topics such as basic information about dementia, the role of caregiver, administrative complications (personal finances, legal documentation) or other relevant interests. Two such sessions were attended, allowing insight into some of the concerns among family caregivers and what information is relevant for them.

Attending staff meetings at the clinic

Two weekly conferences among clinic staff were attended in which patient files are discussed mainly to reach consensus on diagnoses. A further regular meeting between clinic staff and dementia consultants from partner municipalities was attended.

3.1.3 Identified need areas

The data collected from interviews and field notes was analysed to identify different categories of needs from the perspectives of different stakeholders, including patients, caregivers and healthcare professionals. For healthcare professionals, specifically needs in terms of clinically relevant information were investigated. Two additional themes included barriers to care delivery and required attributes or characteristics of technological tools or support for people with dementia, i.e. assistive technology. The results are summarised in Table 3 and discussed below.

Table 3. Summary of information gathered about stakeholder needs during the field study

Person with dementia	Memory function Activities of daily living Psychosocial/behaviour Orientation Safety Care Information
Caregiver	Information about patient and their safety (burden of worry) Care burden (time and effort) Care advice/training Personal, emotional support Information about resources
Healthcare professionals (information needs)	Behaviour Functional capacity Profile Medication list and adherence Individual problems/symptoms Information validation Routine adherence Person with dementias and carer's support needs General health and condition status
Barriers to care delivery	Misinformation Collaboration Process
Attributes of tools for support	Easy to learn to use Easy to remember to use Familiar Adaptable Individualised

Needs of people with dementia

Most of the information about needs of people with dementia related to their memory function, psychosocial needs, and support in activities of daily living (ADLs). This was expressed both according to the problem (e.g. "I forget what I heard a moment before ") and the need (e.g. "I need a way to remember information I am told"). Memory function needs could be remembering appointments (future events), faces and names, placement of belongings, or instructions given by the medical doctor, to name a few. Psychosocial needs range from mood or behaviour related (e.g. apathy, aggression) to social inclusion and mental/physical stimulation.

Caregivers' needs

Information about caregivers' needs related to both the person with dementia and themselves. To care for the person with dementia, caregivers need information about the person's medication adherence, wellbeing etc. Then there are various needs that relate to the impact the condition of their loved one's has on them psychologically (e.g. loneliness, fears for the future), on their time (extra household duties as well as new care duties), and their anxiety levels due to worries about safety (e.g. that the person with dementia will go missing).

Healthcare professionals' needs

These needs relate specifically to clinically relevant information. These included information about patients' behaviour, functional capacity, profile, medication and individual problems - largely depending on where the patient is in their journey through the system. For a new patient, expansive and detailed information is required to build up a profile (e.g. family/home situation, health background, lifestyle, personality) that is used towards both their diagnosis and treatment plan. Throughout the patients care, their functional capacity is of interest. This deals with their ability to perform basic tasks such as eating and washing, as well as memory function (self-reported or test results). The theme "information validation" refers to examples such as asking a caregiver to confirm something the patient has told them. In general, there was a far greater emphasis on trends - changes and their rates - rather than on spot measurements.

Barriers

This information related to barriers that inhibit the care process for various reasons. Misinformation refers to the challenge of invalid or misleading information being shared, such as when the patient is delusional about their activities and consequently misinforms their caregiver (or healthcare professional) that they are taking medication or visiting friends when in reality they are not. These are especially pronounced when the patient lives alone, but also arise when couples have become so interdependent that it is hard to distinguish their individual input into daily tasks and thus the patient's actual functional capacity. An example of a collaboration barrier is conflicting ideas about a treatment strategy - often the patient not desiring treatment. Process barriers include issues such as clinic staff's time being wasted when patients forget appointments.

Attributes of support tools

Of the non-functional needs, usability emerged as the most prominent, especially regarding the effort required to "learn to use" and "remember to use" a tool. The results also indicated that solutions should be familiar, adaptable and individualised.

3.1.4 Mapping a patient journey

Information gathered throughout the field study was used to map a typical journey through the care process, starting with the initial consultation and ending at the point at which their longer term care process is decided. The care process is shown in Figure 5, indicating the interaction point between patient and healthcare providers, its location, focal topic and people involved. Not all steps apply to all patients (e.g. not all patients go on medication or make contact with the dementia coordinator), and not all possible steps are shown (e.g. where neuropsychological testing is included). Also excluded are the full range of tests performed in the initial consultation, which can include blood tests, brain scans and a physical examination. The patient journey ends at a stratification point. This is the point at which the care team decides how stable the patient is across three tiers, each of which represents a different intensity of care, and which decides who is key responsible between the clinic and the patients' regular doctor (general practitioner).

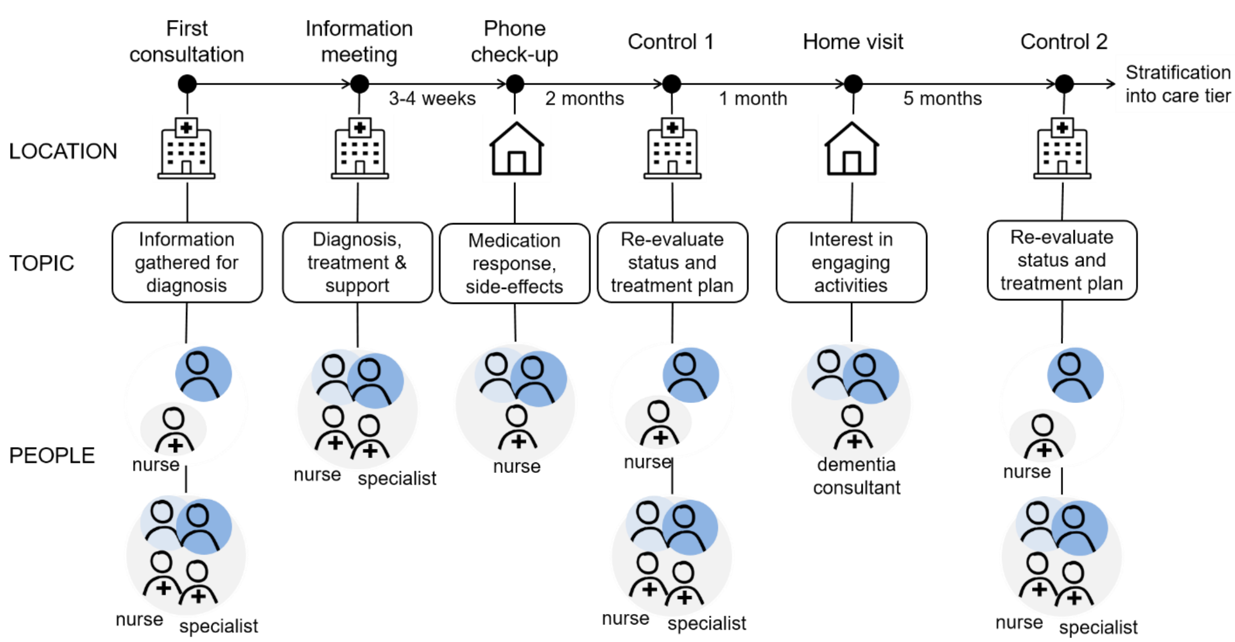


Figure 5. Patient journey through the initial care process at the dementia and memory clinic and connected municipal care

3.1.5 Field study conclusions

The field study provided rich information about dementia as clinical condition and the related care processes and people involved. This also offered valuable insight into real-life experiences and everyday challenges experienced by all involved, which was used to generate a set of need categories from different people's perspectives. Not all needs, processes and people are described in this project to the same level of detail, however these outcomes guided project scoping and provided a valuable reference for a broader picture of dementia care to return to as needed in subsequent project phases.

The focus of the field study has been the arm of support from healthcare professionals to patients and caregivers and how this is formulated. In the next section, we turn our attention from the clinic to the home and explore support offered by technology.

3.2 Matching support needs of people with dementia to capabilities of smart mobile/wearable technology

The aim of this section is to explore opportunities presented by pervasive technology such as smartphones and wearables by relating the roles of assistive technology for dementia to capabilities of a generic mobile/wearable device setup. This is achieved through the following objectives:

1. Review literature to describe existing assistive for dementia and the needs it targets
2. Relate these findings to basic functionality offered by pervasive technology

The first objective builds upon and extends needs identified in the field study from section 3.1, looking particularly at needs met by information and communication technology (ICT). The second objectives outlines potential for mobile/wearable technology to fulfil the identified needs towards defining requirements for a technological setup to support dementia rehabilitation.

3.2.1 Components of mobile/wearable based assistive technology

Mobile and wearable devices are a subset of pervasive technology, upon which the concept of pervasive healthcare is built. Pervasive healthcare describes the use of pervasive technologies for managing health or wellbeing remotely and continuously, within which pervasive assistive technology refers to the use of pervasive technology to enable people with disability to remain healthy, independent and socially engaged [38]. Key components have been described for a pervasive healthcare technology platform [41] and for personal health technology [67]. Both describe components for acquiring and processing data, providing feedback and other services, communicating information and for interaction with the user(s).

Besides potential pervasive healthcare offerings, a typical smartphone/wearable setup presents a range of common applications and sensors for ordinary use in everyday life. Most smartphones today house location and motion sensors, which can be extended by a range of wearable devices (e.g. as fitness trackers and smartwatches). Besides communication functions (calls, messaging, phonebook/contacts), common types of mobile apps include utilities (e.g. calendar, reminders, clock, calculator), social media, leisure or entertainment (games, music player). In the following sections, a range of ICT-based assistive technology for dementia are reviewed such that these can be related to the capabilities presented by the generic setup described above.

3.2.2 Review methods

Literature was reviewed to describe what ICT-based assistive technology for dementia exists and the needs these target. The databases PubMed and SCOPUS were searched to find relevant literature using the search terms *dementia* AND *technology* AND *rehabilitation* yielding 89 results (last retrieved 23 July 2015) of which 38 are ultimately included for analysis. Results using the term *technology* in a biological or pharmacological sense were excluded, as were those referring to use of everyday appliances (e.g. vacuum cleaner, kettle), or describing software aimed at retraining cognitive functions. Where the same group of authors published a series of articles for the same technological concept, only the most relevant is included. Selected articles were analysed to identify needs targeted by the assistive technology described. Findings are presented in Table 4 and discussed in the following section.

3.2.3 Assistive technology for dementia

Assistive technology for dementia ranges from simple devices to larger, more complex systems comprising multiple components and interfaces. Information and communication technology (ICT) employed includes computers, touchscreens, mobile phones, audio players, cameras or microphones in various combinations. These assistive technologies can be loosely grouped into three categories: *interactive technologies*, in which interaction with the user via an interface (e.g. touchscreen or interactive robot) is a primary feature; *ambient assisted living*, involving home sensor networks or home automation concepts; and *tracking/monitoring* technologies intended to track the user's location, position, or activity using carried or worn sensors. Four main themes of needs emerged from the analysis:

- Functional: needs concerning the ability to carry out various cognitive and practical functions
- Psychosocial: needs relating to state of mind and behaviour
- Safety: needs for safety and perceived safety
- Care: needs relating to care management and delivery

Each theme includes several types of needs for which a collection of examples is described below.

Providing functional support

Many studies describe technology to support people with dementia in carrying out activities of daily living (ADL). A common approach is to generate prompts and instructions for tasks such as washing, dressing or preparing meals. Both verbal instructions as well as pictorial cues have been shown to be helpful in such tasks [68]. The COACH system recognises tasks performed in the bathroom and guides users through these [69]. Other examples include help with making phone calls [70]–[72], or navigation tools that help users get to and from home independently [73], [74].

Technology is also used to meet functional needs related to memory loss. The Elderly Day Navigator, part of the Rosetta system [72], uses a touchscreen computer and/or mobile device to remind users of upcoming appointments to support prospective memory (remembering future events). Episodic memory loss can also be addressed by technology: smartphones on lanyards have been used to take photographs at regular intervals during the day, enabling people with dementia and their caregivers to review their activities [75]. This practice is sometimes referred to as *lifelogging* [76], and is used to improve the users' ability to recall recent experiences. Other ways in which technology has also been used to support memory needs include helping users locate objects [70] or remember faces/names [77].

Meeting psychosocial needs

Psychosocial needs relate to factors such as mood, behaviour and social engagement. The need for social connection is partly addressed by solutions that help users make phone calls or navigate. Another approach is to provide a sense of companionship through simulated presence [78] or using animaloid robots as pets [79]. There are numerous examples documenting the use of technology to improve mood and/or behaviour through recreational or stimulating activities. A simple approach is through playing music, which can have a positive effect on mood [68], [70], [78]. *The Companion* is a touch screen device that combines images, music and messages from trusted relations for recreation [80]. The *Engaging Platform for Art Development* (ePAD) is used by people with dementia for art therapy [81]. Technology has also been used for reminiscence therapy, a technique involving recollection of past memories through artefacts such as old photographs or music [82].

Improving safety

A person with dementia's need to feel safe is closely tied to their caregiver's burden of worry about their safety. These needs were frequently targeted by solutions for detecting or preventing adverse events and eliciting help when needed. Falls are of particular importance since cognitive impairment increases both the risk of falling and the likelihood of severe injury from falls [83]. Approaches range from automatic night lighting as a preventative measure [84], to predicting future falls based on physical activity parameters from chest-worn sensors [83]. Wandering is another safety concern that has been addressed using sensors such as wearable GPS trackers [73], [85] or home sensors that detect entry and exit events [86].

Supporting care practices

The examples described so far focus predominantly on the needs of the person with dementia, which is the focus of this review. However, several studies take into account the needs of healthcare professionals and caregivers. One example is an system used to support caregivers by providing informative resources and connecting them to a social network of other caregivers [87]. Several behavioural monitoring approaches were also encountered in which information is generated about the person with dementia's status to trigger intervention or inform care strategies. Tracking technologies have been used to monitor users' mobility, since this tends to decrease as their dementia progresses [47], [88]. Ambient assisted living has been used to monitor nursing home residents for behaviour such as unusually long periods in the bathroom [89]. Functional performance has been monitored using video recording to detect activities of daily living [90].

An overview of support needs within each theme is presented in Table 4. While many examples target several related needs, the most prominent were considered. It should be noted that there exist many interesting and important works beyond those selected for review, and that the sample used is intended to provide an impression.

3.2.4 Relating needs targeted by assistive technology to smart mobile and wearable devices

The collection of needs identified from literature on assistive technology for dementia is presented in Table 4. The two columns appended on the right (shown in light grey) indicate how these needs might be fulfilled using the generic pervasive technology setup described earlier (smartphone and connected wearable sensors). These columns describe ordinary (non-healthcare related), existing applications and on-board sensors that match the target need. Where a specialised tool or service is required, this is indicated with an asterisk (*) if development is fairly straightforward, and with a plus (+) where substantial development effort may be necessary. It should be emphasised that, while the columns on the left show actual results from literature, that the grey columns propose only hypothetical solutions.

Table 4. Relating needs targeted by assistive technology to functionality offered by pervasive technology using a basic smartphone/wearable setup (grey columns). Key to symbols and abbreviations: comms = communication module/apps; (*) healthcare technology development required but straightforward; (+) considerable healthcare technology development required.

	Category	Target need	Examples	Device/apps	Sensors
Functional Support	Activities of daily living	routine reminders	[84]	calendar	
		task instructions	[68], [89], [91]–[94]	*	
		making calls	[71], [72], [84]	comms	
		navigation	[73]	maps	location
	Memory	episodic	[75]	calendar	
		faces/names	[77]	*	
		locate objects	[84]		
		prospective	[72], [95]	calendar	
Psychosocial	Orientation	temporal	[84], [96]	clock	
		spatial	[97]	maps	
	Social engagement	communication	[72], [73]	social, comms	
		companionship	[78], [79]		
	Mood/ behaviour	leisure/entertain	[68], [78], [80], [84], [86], [98]	media, games	
		activities	[72], [81], [99]	games	
		reminiscence	[86], [100]–[102]	*	
Safety	Emergency alerts	elicit help	[73], [103]	comms	
		detect emergency	[72], [86]	+	various
	Prevent/detect	wandering	[85], [86], [89], [103], [104]	+	location
		falls	[72], [83], [84], [86], [89], [105]–[107]	+	motion
Care	Caregiver support	training/resources	[87], [108]	*	
		social network	[87]	*	
	Intervention strategy	decision support	[109]	+	
		assess/monitor	[47], [88]–[90], [110]	*/+	various

3.2.5 Identified potential for meeting support needs with smart mobile/wearable technology

This section has reviewed a body of literature describing assistive technology for dementia to collect and structure the needs these target. The support needs are related to functional capabilities of a generic pervasive technology setup comprising a smartphone and wearable sensors, demonstrating potential for smartphones and ordinary applications to meet these. Limitations imposed by cognitive impairment could make these ordinary applications difficult to use for people with dementia, however opportunities presented for available technologies to provide support are worth further investigation. The use of sensors for monitoring is only briefly touched upon in this section, which focuses primarily on support in everyday life for people with dementia. However, should people with dementia benefit from support offered by pervasive technology such as smartphones, so will this present new monitoring opportunities using sensors on-board these devices. Of the monitoring examples in Table 4, two use location sensors common to smartphones for monitoring mobility (the others include the use of home sensor networks and video monitoring to detect activities of daily living).

We therefore see untapped potential for monitoring function and engagement among people with dementia using commonly available location and motion (activity) sensors. These monitoring opportunities are investigated in the following section.

3.3 Review of behavioural measurement using data from location and activity sensors

This section has been published in *Proceedings of the 21st International Conference on Engineering Design (ICED17).* [21]

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Sensing behaviour in healthcare design
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Vol. 3: Product, Services and Systems Design.
Design Society, 2017. p. 171-181 (ICED, Vol. 17)

Sensing behaviour in healthcare design

Abstract: *We are entering an era of distributed healthcare that should fit and respond to individual needs, behaviour and lifestyles. Designing such systems is a challenging task that requires continuous information about human behaviour on a large scale, for which pervasive sensing (e.g. using smartphones and wearables) presents exciting opportunities. While mobile sensing approaches are fuelling research in many areas, their use in engineering design remains limited. In this work, we present a collection of common behavioural measures from literature that can be used for a broad range of applications. We focus specifically on activity and location data that can easily be obtained from smartphones or wearables. We further demonstrate how these are applied in healthcare design using an example from dementia care. Comparing a current and proposed scenario exemplifies how integrating sensor-derived information about user behaviour can support the healthcare design goals of personalisation, adaptability and scalability, while emphasising patient quality of life.*

3.3.1 Introduction

This work focuses on behavioural metrics within the topic of healthcare design, exploring opportunities presented by pervasive sensing. Designing healthcare systems of the future is a challenging task. These will need to serve the growing number of people in need of care, which together with technological advancement, is driving a shift towards a decentralised healthcare model that relies on home-based care and health management. At the same time, important healthcare goals should also be addressed, including:

- personalised care that takes into account patients' individual needs and desires
- adaptive care that aims to predict and prevent problems; and
- a focus on quality of life and wellbeing rather than a person's disease status alone.

This requires information about people's needs and quality of life to be gathered continuously and on a large scale, and shared throughout a diverse and dispersed stakeholder network. Methods commonly used in healthcare design to gather information about users' needs, such as interviews and observation, are too resource-heavy to be suitably scalable. These methods are typically used to inform a particular design iteration. For the future healthcare paradigm, however, such information should be gathered continuously and integrated into the system. That is, the information is required for operational action in an ongoing process as opposed to design action at a later point in time.

A promising avenue is the use of mobile sensors to gather data about human behaviour. Consumer products such as smartphones and wearables offer sensing capabilities that are increasingly being used for pervasive (or ubiquitous) computing in which data is collected continuously and unobtrusively from users. This data could provide valuable insights into people's behaviour and consequently their lifestyles and general wellbeing. Our aim is therefore to investigate these opportunities and how they might be applied in the design of future healthcare systems. The objectives addressed in this work are to:

- Review literature to find and summarise behavioural measurement approaches using activity and location data
- Demonstrate through an example scenario from dementia care how these might be applied in healthcare design to achieve important goals

Through these objectives, we contribute to the engineering design research community by providing a generic set of behavioural metrics measured with commonly available pervasive technology (e.g. smartphones or wearables) that serves a broad range of applications. These could provide a scalable, data-driven approach to understanding human behaviour in engineering systems.

The following section discusses the use of sensors to study human behaviour in engineering design research and provides a brief background to mobile sensing generally. This is followed by a review of literature to summarise common behavioural metrics obtained using activity and location data from smartphones and wearables. In section 3.3.3, current and proposed scenarios for dementia care are used to demonstrate how behavioural measurement approaches (such as those reviewed) could be applied in healthcare design to achieve the aforementioned healthcare goals. A discussion on this work's implications for engineering design, pinpointed limitations and future work is presented in section 3.3.5, followed by a conclusion in section 3.3.6.

Sensing behaviour with pervasive technology

Engineering design research has long since examined human behaviour and its role in design. A distinction can be made between the behaviour of designers and that of users, customers or other stakeholders. Studying the behaviour of designers helps us to understand and improve the design activities or processes that they engage in [111]. Studying the behaviour of users, customers or other stakeholders is an established approach towards gathering information about unmet needs or how people interact with designed artefacts. Understanding the behaviour of customers/users also plays a pivotal role in behavioural design, which describes the design of products or interventions that incorporate behaviour change strategies [112].

So far, sensor-based behavioural measurement has barely penetrated engineering design literature, with only a handful of examples. Sensor data on designer behaviour has been used for automatic detection of designers' emotional states to better understand design team interactions [113], and to relate design activities to physiological responses [114]. While both studies use sensors to measure behaviour, neither quite falls into the category of pervasive technology, which takes advantage of the portable, unobtrusive nature of the latest wearable and mobile devices. In this regard, an interesting case from the hearing aid industry is presented in a study on instrumenting the user [115]. Here, behavioural data collected from hearing aids and smartphones is used to discover unidentified user needs, complementing existing qualitative methods. The data collected and the measures derived are somewhat specific to each of the examples described and may be difficult to transfer and apply in other design challenges. A far broader range of sensing approaches and analysis methods is presented in a survey of new digital technologies that can support design research, particularly for understanding users' needs and behavioural patterns [116]. We build upon this work by demonstrating how such sensing approaches can be applied in healthcare design. In this section, we review literature to collect examples of behavioural measurement in terms of common sensors, data, metrics and analysis approaches. First, a brief background on mobile sensing in healthcare and beyond is provided below.

Wearable and mobile sensing

Wearable sensors offer vast advantages over their bulky, cable-heavy predecessors and have over the years already seen expansive use in healthcare in applications ranging from chronic disease management, neurological disorders, and rehabilitation, to stress monitoring and emotion detection [117]. The portability and unobtrusiveness of mobile sensors has enabled measurement to extend beyond the clinic into people's normal daily lives, blurring the boundary between medical devices and consumer products. Our smart devices (smartphones, wearables, tablets etc.) are packed with sensors that are increasingly being applied in pervasive healthcare and related fields (mHealth, ubiquitous computing) [38], [118].

Sensor-derived behaviour measurement is also gaining momentum in other fields. The ability to gather rich behavioural data from smartphones allows insights into people's behaviour on a larger scale than ever before. The relevance of mobile crowd sensing for research in social sciences and other fields is recognised by Xiong et al. (2016), who present a general-purpose mobile sensing platform for such purposes. A decade earlier, wearable sensors from mobile phones were already being used to understand complex social systems using an approach termed reality mining [42]. This work has been developed and built upon extensively over the years in research using mobile and wearable sensors to measure, understand and influence human behaviour and interactions – from mobility and daily cycles to friendship and social networks [43]–[45].

3.3.2 Behavioural measurement: sensors, data, features and analysis

When it comes to measuring and understanding human behaviour, information about location and activity is used extensively. This is not surprising, since our behaviour can largely be characterised by where we go and what we do. Location and activity information is also easily obtained using popular consumer products (including common smartphones) making it fit for generic use in a wide range of applications. Even where a particular case requires the use of other, more specialised sensors (e.g. microphones in hearing aids or blood glucose monitors for diabetes management), one can reasonably expect smartphones to be used either in conjunction with those sensors or independently by the user in everyday life. We will therefore narrow our focus to these two modalities.

Literature was reviewed to collect examples of behavioural monitoring using activity or location data from smartphones and wearables. These are used to describe common approaches in terms of the sensors used and data these yield, metrics calculated from this data, and how these have been analysed further. The results are summarised in Table 5.

Table 5. Sensing user behaviour: common sensors, data, metrics and analysis from behavioural measurement studies using activity and location information

	Sensors used	Data extracted	Metrics calculated	Further analysis
Location	*GPS Wi-Fi Bluetooth GSM	Positions (latitude, longitude) in a series of stops and moves	Total distance, area or perimeter Action-range Standard deviation of displacements Number of trips Time outside home Time at certain places (or types of place) Transitions between places	Routine index Geographical network analysis Entropy Eigenbehaviours Event detection
Activity	*Accelerometer *Gyroscope *Pedometer Magnetometer Barometer Microphone	Activity bouts for different activity states or types (at varying levels of detail) Steps Cadence Activity intensity Energy expenditure	Total steps Bout durations or ratios Number of bouts Transitions between activity states/types Variation in activity states/types	Relation to personal goals Event detection Change detection Temporal structure (trend gradient, probability density, similarity across time scales) Structural complexity

*Primary sensors used for the specified data collection purpose.

Location

Location refers to the user's geospatial or position data, which can be collected from smartphones using GPS, possibly in combination with Wi-Fi, GSM, cell-tower or Bluetooth information. Location data typically comprises time-stamped positions (latitude, longitude) that are then used to extract a series of stops and moves termed mobility traces.

Various features can be calculated from a user's mobility traces. Lifespace refers to the size of the space in which a user carries out their daily life and includes metrics such as the total distance, area or perimeter covered [47]. These have been applied together with measures of the maximum or average distance from home (action-range), time spent outside of the home, and number of trips from home in studies involving the elderly [120] and people with dementia [47]. A study on mental health using a similar set of mobility metrics further includes standard deviation of the displacements and analyses temporal patterns using a routine index that quantifies how different the places visited by a user are from one interval to another [121].

Time spent at stops can be used to identify specific points of interest (POI's). In the *SensibleDTU* project, mobility traces from students are used to study human mobility by measuring geographical networks (POI's as nodes and paths between these as edges), time spent at POI's and the number of POI's visited over time [122]. A study on social anxiety among college students specifically identifies work, home, social, religious and transportation places to calculate time spent at each type and the frequency of transitions between type pairs [123]. Research involving reality mining groups places into work, home or other. Here, temporal patterns are analysed by examining how users move between these places over time to calculate entropy and derive eigenbehaviours that characterise their mobility behaviour or lifestyle [42], [124]. Measures based on location data (together with activity and other data) have also be analysed further for recognition of individual behavioural patterns to detect unusual events [125].

Activity

Smartphones contain several sensors that can be used to measure physical activity (or movement). Accelerometers are most common; however gyroscopes and pedometers are also used, as well as magnetometers, barometers and microphones [126]. Numerous algorithms have been developed for these sensors to generate data such as steps, energy expenditure estimates, activity intensity, postures and gait characteristics. In turn, this data can be used to identify a wide range activity types or states at varying levels of detail (low- and high-level features): from active or sedentary states to positions/movement (e.g. walking, sitting, standing and lying) or even types of daily activities, physical exercise or transport modes.

A common approach is to measure the duration and number of bouts for activity types. This is measured for walking bouts along with total steps and step time (cadence) to examine mobility among people with dementia [47]. An example involving patients with chronic illness further relates the time spent in an activity to a personalised goal [127]. Duration ratios for walking, sitting and standing activities are analysed further to describe activity patterns in stroke rehabilitation by examining trend lines in these measures, specifically the gradient and offset [128].

Monitoring changes in behaviour, e.g. based on lifestyle changes to meet a certain goal, is the focus of work describing a Physical Activity Change Detection (PACD) approach [129]. This uses activity type, intensity, duration and frequency to detect behaviour change and determine its significance. Patterns in activity are also analysed in a study that examines changes in activity behaviour in relation to health and ageing. This uses measures including activity type (sedentary, active, walking), intensity, steps and cadence. Variation within and transitions between these are also measured. Patterns are then analysed in various ways: univariate patterns are analysed using the probability distribution function (PDF), cumulative distribution function (CDF) and the detrended fluctuation analysis (DFA), which measures similarity of activity bouts across different time scales; multivariate patterns are analysed by modelling the activity pattern as a multi-state process and calculating structural complexity [130].

The work described in this section comes mainly from technology sciences, which tend to focus on the path from sensing technologies to analysis methods, with less emphasis on integration into wider healthcare systems. Healthcare design could complement this by addressing the further steps and considerations necessary for implementation in practice. In the following section, we will shift to the role of healthcare design, demonstrating how these steps might unfold in the design of future dementia care

3.3.3 Demonstrative example from dementia care

As a demonstrative example of using sensor-based behaviour measurement in healthcare design, we will examine the design of a dementia care system. The rising prevalence of dementia due to an ageing population presents a considerable challenge in terms of both the burden this will place on healthcare systems and the quality of life for those affected. We will therefore investigate how pervasive sensing could be integrated into the design of a dementia care service to help sustain quality of life for a growing number of people with dementia, while meeting overall healthcare design goals of delivering personalised and preventative care.

Our focus is the process from the patient's first visit to the clinic onwards for those in the early stages of the disease. The target group includes people with a mild-to-moderate cognitive impairment who live at home in the community (as opposed to residents in a care facility). For this group, independence and social engagement are important aspects of quality of life, and home-based (distributed) care is particularly relevant.

Two scenarios are presented: current and proposed. The first is representative of current care practices and is based on our knowledge and experiences working closely with a dementia clinic in a Danish hospital for over 3 years in various research projects. The latter is an extension of the first, integrating behavioural measurement using pervasive technology.

Current scenario

Peter is a 71-year-old retired sales consultant who lives with his wife, Anne. Based on concerns both Peter and Anne have had about Peter's increasingly forgetfulness, their doctor refers them to a memory clinic. During their first visit to the clinic, Peter and Anne meet a nurse and a specialist doctor with whom they discuss at great length Peter's symptoms, general health and home life, especially regarding his functional capacity. Peter also undergoes several assessments and physiological tests. The test results and consultation notes are later discussed in a routine meeting among the clinic staff who together decide that Peter is in the early stages of Alzheimer's dementia.

Peter and Anne return to the clinic for an information meeting during which they are informed about Peter's diagnosis, a proposed course of medication to reduce his symptoms, and about support offered by the clinic and municipality. After 3-4 weeks, the nurse calls to check up on Peter regarding the impact and any side effects of the medication. Peter and Anne visit the clinic again 3 and 9 months after Peter's treatment started according to a predefined schedule. Each time Peter's medication is again addressed and adjusted if necessary, his memory assessed, and his home life discussed. At the second control examination, it is clear that Peter's condition has declined significantly and the medication is no longer keeping his symptoms at bay. His memory impairment is considerably worse, and based on their interview, the specialist suspects that Peter has given up on many of his interests and become reclusive and depressed. Anne is noticeably worn out. She mentions that she called the dementia consultant in their municipality to ask for advice, but that by that time Peter was already spending most of his time alone at home and had no interest in meeting the dementia consultant or following her suggestions. The clinic staff talk to Peter and

Anne about the future and suggest moving Peter to a care facility to relieve Anne and provide Peter with necessary support.

Proposed scenario

In this scenario, Peter owns a smartphone. He has used it for some time prior to the onset of his dementia for much the same purposes many of us do today: calendar, reminders and note-keeping; entertainment; social connection and communication.

At Peter's first consultation at the clinic, the nurse suggests an app for his phone to gather data about his behaviour, such as how much he goes out and how active or restful he is when home, explaining that this will aid their future discussions about his lifestyle and how this changes over time. She also recommends a smartwatch to wear instead of having to remember to carry his phone.

When Peter and Anne are informed about Peter's diagnosis, the specialist asks them about specific goals Peter has for his own independence and quality of life, for which Peter provides two:

- Continuing to handle the grocery shopping, one of his main contributions to the household work
- Maintaining an active social life, which he is concerned will decrease as his hobbies become more difficult for him to participate in.

They set up Peter's app to track measures related to his goals. For the first, they track how often he visits the local grocery store. For the second, they choose to track how much time he spends outside the home as an indicator of his social life. The specialist suggests a further measure: entropy in his daily pattern. The specialist has advised that Peter adhere to a routine already in the early stages of the disease, since maintaining this structure will help him to manage as his condition declines. Peter and Anne agree to share this information with the clinic as well as the dementia consultant from their municipality.

A phone check-up replaces a full assessment in the first control, since it is clear from the data being generated that Peter's condition is stable. Shortly afterwards, however, the app notifies the dementia consultant that Peter's trips to the grocery store have stopped and that he is spending more time at home. She arranges a visit to discuss any obstacles Peter is experiencing and how these might be overcome. She helps him set up a notification on his smartwatch to remind him of his grocery list as he arrives at the store, and suggests activities at the local care centre to replace hobbies he can no longer manage. Furthermore, she contacts the clinic and suggests bringing his next control forward. At the control, his assessment shows that his impairment has worsened, however he is performing satisfactorily in everyday life, particularly in relation to his own goals. They decide to continue as usual until his next control.

An overview of how the current scenario is extended to include behavioural measurement in the proposed scenario is depicted in Figure 6. Core differences in the proposed scenario compared to the current scenario include:

- Continuous measurement
- Addition of objective information to assess lifestyle and behaviour
- Adaptation to the predefined care plan
- Specification of individual goals for quality of life in the care strategy

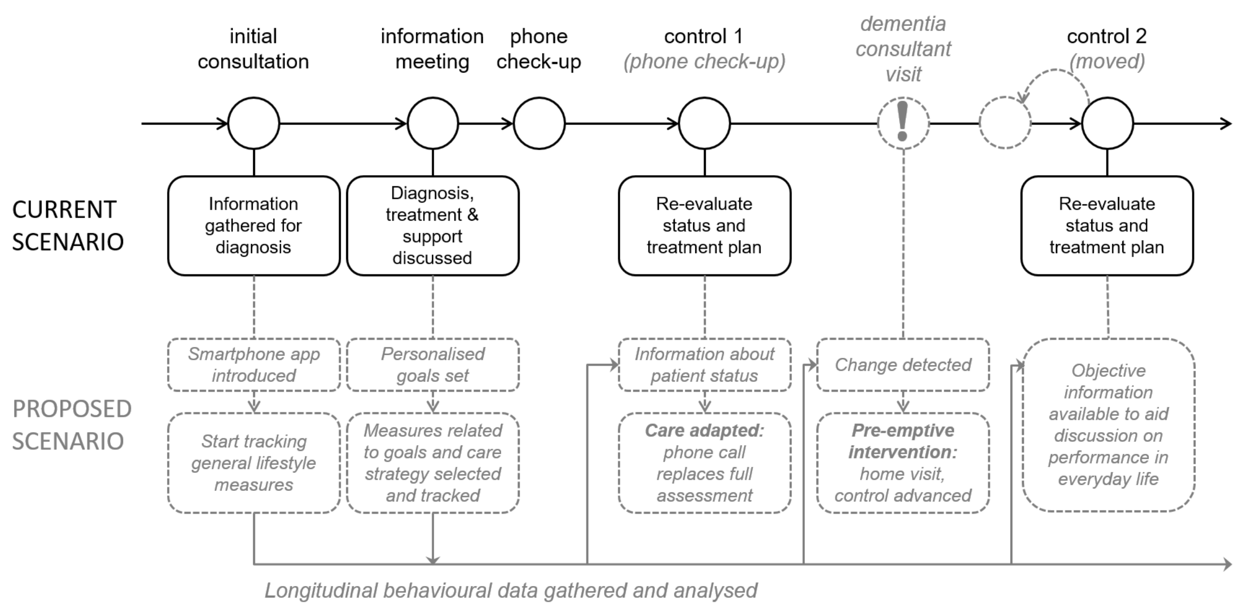

Figure 6. Process from first visit to the clinic until the second control showing the current scenario (black) and how this is extended or altered in the proposed scenario (grey)

3.3.4 Comparing the two scenarios in relation to healthcare design goals

Comparing the proposed scenario to the current scenario demonstrates how behavioural sensing can be used to meet key healthcare design goals listed in the introduction.

Personalised, patient-centred care:

An example of personalised care demonstrated in the proposed scenario is the selection of features according to the patient's individual goals. Furthermore, information provided through behavioural measurements helps healthcare professionals to make suggestions based on patients' specific needs or lifestyle, for example the use of a smartwatch notification when Peter stops grocery shopping.

Adaptive and pre-emptive care

In the current scenario, information about the patient's condition is provided through assessments and patients' (or caregivers') perceptions, with long intervals between inputs. In contrast, the behavioural sensing provides continuous, objective information far better suited to early detection of an event or decline. This enables the preventative care model described in which Peter's decline in performance is detected early enough for an intervention (home visit from the dementia coordinator) and adaptation to his care strategy (control brought forward) help prevent his transfer to a care facility.

Scalability (and resource efficiency)

In the proposed scenario, pervasive technology generates vast information without relying on patients and their caregivers to actively report on events and behaviours nor on input from healthcare professionals. Furthermore, insights into Peter's lifestyle can aid discussions about his performance, allowing healthcare professionals to ask targeted questions that could reduce the time spent trying to understand how his behaviour is changing.

Emphasis on quality of life and wellbeing

In the proposed scenario, behavioural sensing is used to measure aspects of the patient's wellbeing to complement information about symptoms and medication response. This shifts the focus from functional capacity to performance in everyday life.

3.3.5 Discussion

We have presented a generic selection of behavioural metrics and demonstrated their application in the example of designing pervasive dementia care. We will now discuss the importance of this work for healthcare design and beyond to engineering design research and practice generally, and pinpoint important limitations and areas for further study.

Bringing healthcare design into the conversation on pervasive sensing

The concepts presented in this work (sensing behaviour) have to date remained predominantly within the domain of technology sciences. The considerable progress made in these fields is of marked importance and is driving a revolution in healthcare. However, within the bounds of these fields, the focus remains mainly on the technology and information systems. Bringing this topic to the healthcare design agenda could accelerate progress and implementation in practice by including a holistic systems perspective and service design focus. This work contributes by bridging technology and design domains and promoting the adoption of behavioural sensing in design research, particularly for healthcare.

Implications for engineering design beyond healthcare

The generic, widely applicable behavioural measures presented in this work provide a starting point for engineering design researchers and practitioners to adopt data-driven approaches to understanding human behaviour. There are countless opportunities for monitoring behaviour to support engineering design research. The behavioural design process presented by Cash et al. (2016) includes several steps that require information about behaviour (e.g. defining a behavioural problem, field work and iterative testing of an intervention). Design of transport systems, smart cities and other engineering systems can be supported by information on population behaviour using mobile crowd sensing approaches. These combine sensor data with data from social networks to gather and share various types of information such as location, context, feelings and opinions, traffic conditions or pollution levels [131]. Since studying complex sociotechnical systems is at the root of engineering design research, such tools for understanding human behaviour could greatly advance the field.

Limitations and future work

This work uses scenarios to present a concept and demonstrate its potential. Although this method was informed by close collaboration with experienced healthcare professionals, the proposed scenario should be tested in practice before further conclusions can be drawn about its benefits for healthcare design. Real-life testing is recommended to overcome the following limitations:

- It is unknown whether the level of use of the technology among people with dementia would be sufficient to generate the required data.

- The behavioural metrics presented are often measured using data collected under controlled conditions that may not represent real life (even "real-world" data collection tends to occur under strict protocols, e.g. specific device placement or use instructions).
- Further evidence is required to determine the impact of using behavioural sensing in healthcare design for the goals described (personalisation, adaptability, scalability, focus on wellbeing). While potential advantages are put forward, a thorough evaluation is beyond the scope of this work.

While we have focused specifically on activity and location data from smartphones or wearables, this can be combined with numerous other data sources. Future work should consider the opportunities presenting by sources such as: user interactions with the device; features based on social activity (e.g. calls and texts); and experience sampling, which utilise the pervasiveness of smartphones to collect information from users about their experiences in-the-moment [115].

3.3.6 Conclusion

This work addresses the need for scalable, data-driven approaches to measuring and understanding human behaviour in the design of future healthcare systems. As our main contribution, we present a generic set of behavioural metrics and a simple, conceptual description of their application in healthcare design.

Literature is reviewed to identify behavioural measurement approaches based on activity and location data that can be gathered using smartphones and wearables. These are used to present a collection of behavioural metrics, along with common sensors and data used to calculate these and examples of further analyses.

One healthcare area that could benefit from behavioural monitoring is dementia, which is increasing in prevalence and placing a large burden on healthcare resources. We have demonstrated through two scenarios (current and proposed) how using behavioural measurement in the design of a pervasive care system for dementia could help to achieve important healthcare design goals including personalisation, adaptive/pre-emptive care, scalability and a focus on quality of life.

The behavioural sensing approaches described could support a wide range of healthcare design challenges beyond dementia in future as we make the transition towards connected, distributed healthcare systems. Insights into human behaviour provided by continuous, objective measurement could further support the design of many other engineering systems.

References

Article references are merged with thesis references for document continuity. Reference numbering in this section is therefore adapted from the original publication.

Chapter 3 conclusions

This chapter has explored the PhD topic through empirical methods and review of literature. This has informed about the care process involving healthcare professionals, people with dementia and their caregivers in section 3.1, and thereafter investigated potential support and monitoring opportunities presented by generic mobile/wearable devices and applications.

Four categories of identified needs include: ***functional****,* ***psychosocial****,* ***safety*** *and* ***care****.*

Section 3.2 has shown that functional, psychosocial and safety needs could potentially be addressed using smartphones in combination with the following types of applications:

- *Calendar for remembering ad-hoc or routine tasks and appointments*
- *Maps for navigation support*
- *Calls/messaging for facilitating communication*
- *Clock/weather/other home screen display for orientation*
- *Emergency services app or favourite contact shortcut as an "panic button" to elicit help when distressed*

The article provided in section 3.3 and published in [21] *has indicated that care processes could be supplemented by a range of monitoring opportunities presented by sensors common to most smartphones, including:*

- *Location sensors to measure mobility (the extent an individual travels outside of their home)*
- *Activity sensors (accelerometers/pedometers) to measure activity types, levels or patterns*

These findings are applied in the following chapter to create a prototype technological setup to fulfil these support and monitoring roles.

Chapter 4

CREATE

Objective 2: Create a technical solution by combining and adapting existing devices, sensors, applications and algorithms to support dementia care

The previous chapter identifies potential opportunities for technology to support people with dementia's needs and monitor their behaviour to inform care processes. We now take a step towards putting these ideas into practice. This chapter describes how devices, applications and algorithms are selected, adapted and tested to create a technological setup for support and monitoring, thereby fulfilling objective 2.

The main contribution of this chapter is documented in a journal article entitled "Development of a sensor-based behavioural monitoring solution to support dementia care" forming section 4.2. This focuses on the translation of data from location and activity sensors to behavioural measures (or features) that are meaningful and relevant for informing dementia care strategies. An overview of the code developed in this article is provided in Appendix E, and the custom application used for collecting device data is illustrated in Appendix D.

Prefacing the article, section 4.1 describes a preliminary step in the development of the technical setup: the selection of hardware and software (devices and applications). The section is based on the journal article "Pervasive assistive technology for people with dementia: a user-centred design case" [1], provided in Appendix B.

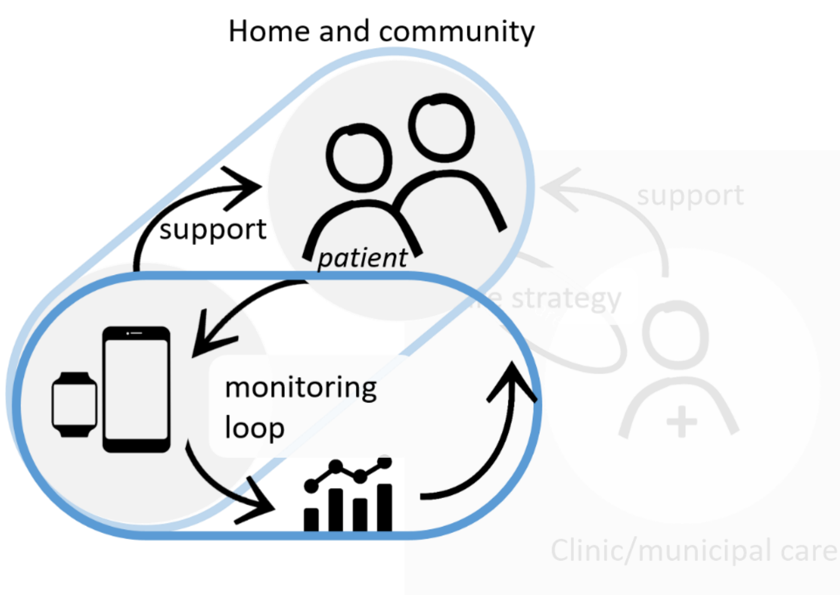

Figure 7. System viewpoints employed in this chapter. Section 4.1 (lighter blue) focuses on support from technology, and section 4.2 (darker blue) on sensor-based monitoring.

4.1 Preliminary development: device selection and testing

Chapter 3 identified potential opportunities for commonly available devices and applications (apps) to address needs of people with dementia regarding support for functioning in everyday life, safety or psychosocial factors. This was based on matching identified needs to functionality offered by technology, however does not take user acceptance and adoption into account. Issues such as usability are particularly important among people with dementia for whom cognitive impairment, as well as other age-related factors, may limit their ability to use technology often targeting younger, healthy individuals.

To address user acceptance and adoption, a user-centred approach to device and app selection and testing was carried out with end-users (people with dementia). This phase was completed together with two masters students as part of their thesis project, and is described in detail in the article *Pervasive assistive technology for people with dementia: a user-centred design case* [1] provided in Appendix B.

A smartphone and smartwatch were selected that run Android operating systems for flexibility in further development, as well as based on available sensors and factors such as screen size and battery life for ease of operation. These included a Sony Xperia E4 and Sony Smartwatch 3 (shown in Figure 8). Applications were selected to fulfil the functional requirements outlined at the end of Chapter 3, including: calendar/scheduling, navigation support (maps), orientation, communication, and emergency help.

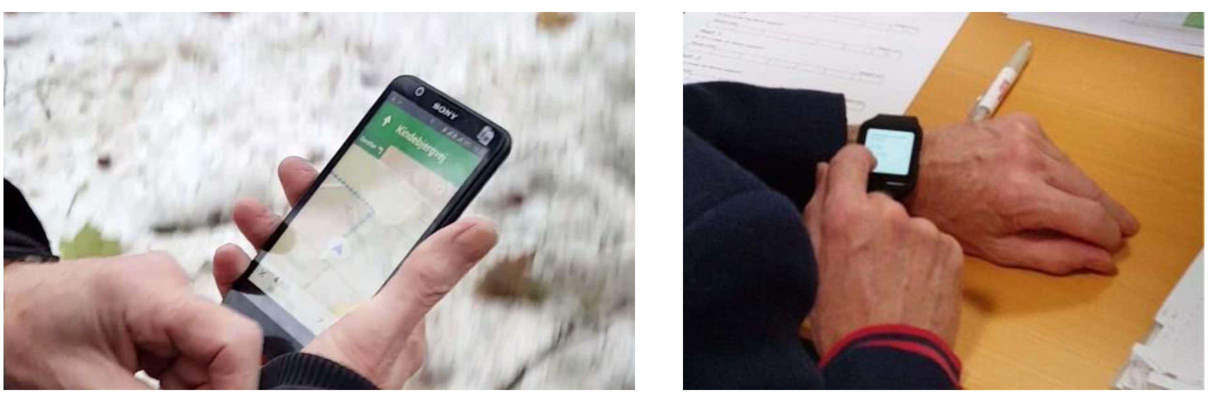

Figure 8. Testing usability of the devices and applications among people with dementia

The setup was tested among five people with dementia and their caregivers. Controlled usability testing is followed by field testing in a real-world context to gather data from video recordings, interaction logs, system usability scale questionnaires, logbooks, application usage logs and interviews structured on the unified theory of acceptance and use of technology model. The data is analysed to evaluate usability, usefulness and user acceptance. The results showed promise for user adoption overall, and led to the following conclusions and recommendations for further studies:

- Personalisation and familiarity highlighted as key considerations
- Calendars/scheduling were most successful and navigation least in terms of usability and usefulness.
- Smartwatch to be used as an output device only, based on poor usability regarding user-interaction (e.g. trying to input data into apps via the smartwatch was difficult for users)

Based on these findings, the decision was made to restrict support offered to future participants to calendar/scheduling functionality and a home screen with basic information, with any additional support to be based on pre-owned (familiar) tools or individual needs. As recommended, in further studies the smartwatch is offered to participants for reading output only, that is, as a means of receiving notifications or reading the time/date from the watch face. The smartphone was later changed to another Android phone (Nexus 5) for further development due availability of an on-board step counter to circumvent the need for third party applications or additional processing to access step-count counter from other sensors (e.g. accelerometers).

Following this pilot phase is the development of a complete behavioural monitoring setup to access sensor data and use this to calculate a set of mobility and activity measures. Development of the data infrastructure required to access sensor data was carried out in collaboration with an external contractor and is described in subsection 4.2.3 of the following section. Development of a set of algorithms to measure behaviour based on location and activity sensor data is the primary contribution of this part of the thesis and manifest in the submitted journal article presented in the following section.

4.2 Development of the behavioural monitoring solution

This section has been published in *JMIR Preprints* while under review for publication in *JMIR mHealth and mHealth* [17]. Further information to supplement the article is provided in Appendix D illustrating an overview of the custom applications used to collect device data, and in Appendix E illustrating an overview of the code structure for behavioural feature extraction.

Thorpe J, Forchhammer BH, Maier AM
Development of a sensor-based behavioural monitoring solution to support dementia care
JMIR Preprints. 23/08/2018:12013
DOI: 10.2196/preprints.12013
URL: https://preprints.jmir.org/preprint/12013

Development of a sensor-based behavioural monitoring solution to support dementia care

Abstract:

Background: Mobile and wearable technology presents exciting opportunities for monitoring behaviour using widely available sensor data. This could support clinical research and practice aimed at improving quality of life among the growing number of people with dementia, but requires suitable tools for measuring behaviour in a natural, real-life setting that can be easily implemented by others.

Objective: The objectives of this study are to develop and test a set of algorithms and metrics for measuring mobility and activity, and describe a technical setup for collecting the sensor data these require using off-the-shelf devices.

Methods: A mobility measurement module is developed to extract GPS trajectories and home location from raw location data, and use these to calculate a set of spatial, temporal and count-based mobility metrics. Activity measurement comprises activity bout extraction from recognised activity data, and daily step counts. Location, activity and step count data is collected using smartwatches and smartphones, relying on open-source resources as far as possible for accessing data from device sensors. The behavioural monitoring solution is evaluated among five healthy subjects who simultaneously logged their movements for one week.

Results: Evaluation showed that the behavioural monitoring solution successfully measures GPS trajectories and mobility metrics from location data, extracts multimodal activity bouts during travel between locations, and that step count from a wearable device could supplement this with information about daily activity including during stay periods between trips.

Conclusions: The work contributes to clinical research and practice by providing a comprehensive behavioural monitoring solution for use in a real-life setting that can be replicated for a range of applications where knowledge about individual mobility and activity is relevant.

Keywords: *behavioural monitoring, mobility, activity, dementia, P4 healthcare, lifespace, wearable sensors, mHealth, uHealth, active ageing*

4.2.1 Introduction

The ageing of the population and consequent rise in prevalence of conditions such as dementia presents a great challenge to society [54]. New care approaches are needed to overcome the increasing disparity between available resources and demands on our healthcare systems. Mobile and wearable devices, and the rich, health-related data these generate, present exciting opportunities to broaden access to care whilst enabling predictive, preventive, personalised and participatory (P4) healthcare interventions [132]. One interesting avenue is the use of sensor data to monitor behaviour. Individual mobility and activity is highly meaningful regarding independence and quality of life among people with dementia [21], and could be measured using data recorded from smartphones and wearables, such as location, activity, and step count.

Relevance of behavioural monitoring for dementia care

Out-of-home mobility (also referred to as *lifespace* or *global* mobility) describes the extent to which an individual moves within their environment by any means. Both increasing age and cognitive impairment are associated with reduced mobility [133], [134]. This is of great concern regarding quality of life for people with dementia, since mobility is intrinsically linked to social engagement, functional capacity, affective state and caregiver burden, and a decisive factor for active aging [134]–[137]. Several factors may be at play when cognitive impairment leads to reduced mobility, such as concerns about safety, usual activities becoming too cognitively demanding, and depressive symptoms (e.g. reclusiveness and apathy). Reduced mobility can present a dangerous feedback loop by inhibiting social engagement and stimulation, thereby aggravating the cognitive decline and depressive symptoms that contribute to further mobility reduction. This underscores the importance of maintaining mobility among the elderly and especially the cognitively impaired. Activity can include physical activity levels or activity states/types. While physical activity is directly linked to mobility in that a person's functional capacity contributes to their ability to move in their environment, its measurement also complements out-of-home mobility measures by informing about how active a person is while home (or stationed at other locations). Monitoring activity is relevant among people with dementia in several ways. For rehabilitation, activity monitoring can guide strategies for increasing engagement in meaningful activities [51], and provide insight into how structured an individual's daily routines are. Activity levels also provide a useful indicator for functional capacity loss with cognitive impairment. Some studies have even shown a possible association between physical activity and reduced risk of dementia or dementia progression [138].

Related work and open challenges

Measurement of mobility and physical activity has traditionally been performed using surveys. This approach is limited by its reliance on patients' memory and subjective perceptions of values such as the distances they cover or time spent active each day, which is especially problematic among people with cognitive impairment. Surveys require input from both patients and healthcare professionals, and thus tend to be restricted to discrete measurement at widely spaced intervals with no information about changes that occur daily or even weekly or monthly. The last decade has seen significant progress towards sensor-based behaviour measurement, including among the elderly and cognitively impaired. Mobility and activity features have been calculated using specialised GPS kits and ankle-worn accelerometers [48], [133], [137], [139]. Recently more works have leveraged the wide availability and acceptance of today's personal devices. Smartphones and wearables have successfully been applied to measure activity among frail and functional older adults under free-living conditions [140], daily step count and distance covered among people with dementia [141], and lifespace (distance, time at home, trips) among people with Parkinson's disease [49]. While these works offer valuable contributions towards sensor-based behavioural monitoring, they remain difficult to apply directly in clinical research and practice. Some employ specialised systems that may be difficult to replicate, or prescribe strict protocols regarding device placement and use that may not be realistic for long-term, everyday use. The selections of metrics varies substantially, as do the methods used to calculate them and the data required as inputs. For example, some metrics are calculated from raw GPS logs while others require knowledge of travel trajectories, often dependent on regularly sampled data or substantial pre-processing. How behavioural measures are calculated affects clinical relevance for a specific target group. For example, an approach to classifying location data as *at home* is to use a distance threshold of 500 meters from the statistical mode [49], while robust against poor location accuracy, this may not be best suited to target groups with low mobility whose trips out of home are often within this range. We therefore recognise the need for a behavioural monitoring solution that can be easily implemented using available devices to measure a comprehensive set of mobility and activity features, that is suitable for use among elderly and cognitively impaired users living at home in the community.

Objectives

The main objective of this work is to develop and test a complete set of tools for measuring mobility and activity using widely available data from off-the-shelf devices. We furthermore describe a generic setup for collecting the required data. Together, these are intended to fulfil the purpose of monitoring behaviour on an individual level to observe patterns or changes among community-dwelling, older adults such as people with early-stage dementia. Two important goals include:

- Transferability: others should be able to implement the solution at minimal additional effort or expense.
- Real-life suitability: the solution should be developed for long-term, unsupervised, everyday use rather than laboratory test conditions.

Through fulfilling these objectives, this work contributes with a comprehensive behavioural monitoring solution to advance clinical research and practice and enable P4 healthcare systems.

4.2.2 Methods: Extracting features and metrics from behavioural data

Here we describe the methods used to measure mobility and activity from sensor data, including the algorithms that were adapted and developed for this purpose. We have chosen to focus on three types of data: location, step count and recognised activities, since these are both widely available and highly relevant for measuring mobility and activity. All algorithms and calculations described in this section were implemented in the R programming environment and available on a public repository *[pending article publication, available on request]*.

Mobility measurement

Mobility measurement has been described in a number of works for chronic diseases, mental health, and among the elderly [121], [142]–[144]. These works describe a variety of metrics, which we categorise here as spatial, temporal or frequency-based. Spatial measurements, often termed *lifespace,* include geographical areas or distances covered, such as the area of the minimum convex polygon (MCP) enveloping a specified quantile of GPS coordinates, distances from home (action range), or total distance covered. Temporal measurements include time spent at or out of home, or visiting places of interest. Frequency-based measure include counts within a given period, such as the number of trips out of home or places visited per day or week. Certain lifespace measures can be calculated from raw GPS data, whereas other metrics require knowledge of a home location, and some require knowledge of GPS trajectories, that is, the series of stays and moves within the location data.

The raw location data for each user comprises merged watch and phone data including timestamp, latitude, longitude, and accuracy in meters. The sampling frequency is irregular and, besides periods of missing data e.g. due to signal loss, readings are spaced between a few milliseconds and ~5 minutes apart. The only pre-processing applied was to filter the data according to accuracy with an upper limit of 25 meters. The inputs required to calculate the mobility metrics include the set of coordinate pairs, GPS trajectories (a series of stays and moves), and a known home location. The following sections describe how these inputs are obtained, followed by a description of the metrics calculations.

Extraction of travel trajectories and home centroid:

Many temporal and frequency-based measures require GPS trajectories describing how the person stays at or moves between locations, also referred to as *mobility traces* [121]. This requires analysis of the raw location data to extract *stay* (or *stop*, *visit*) and *move* (or *go*) events, and identification of geolocations (or *points of interest*, *hotspots*) in the dataset. The identification of trajectories follows a similar approach to those described in literature [122], [145], [146], whereby the data is first split into *stays* and *moves* using time and/or distance thresholds, and then clustered to identify geolocations in the dataset. We further include a filtering step to merge temporally close stays or moves that likely belong to the same event. An overview is provided in Figure 9..

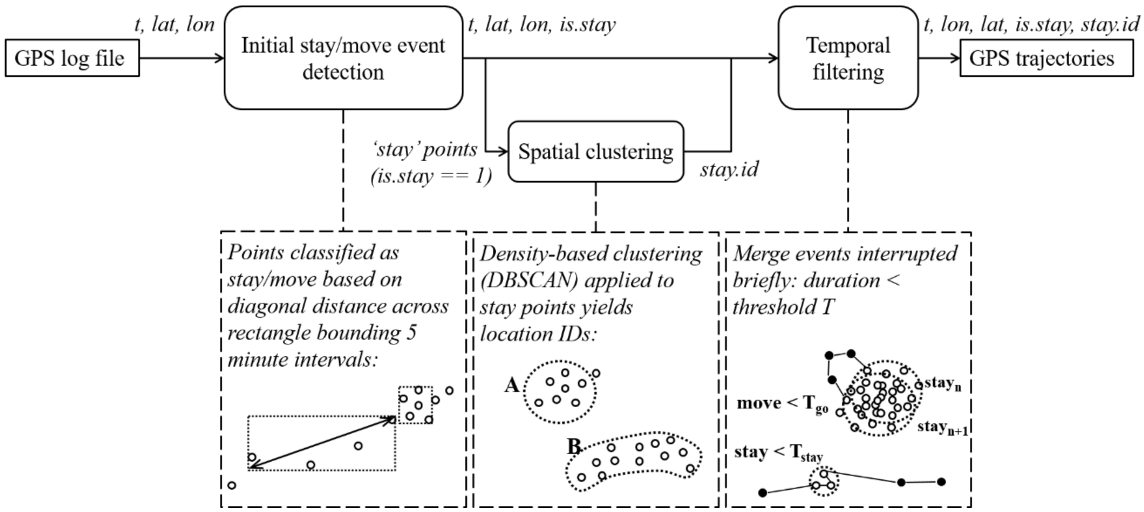

Figure 9. Overview of the trajectory extraction algorithm

The initial stay detection step combines both time and distance information (as in [146]) to accommodate irregularly sampled location data without the need for further pre-processing. For each location, a rectangle is calculated bounding data from intervals of five-minutes ahead. If the diagonal distance across the rectangle exceeds a predefined threshold, the point belongs to a *move*; if below the threshold, all points in the interval are classified as *stay* points. The stay points are then clustered into distinct locations using the DBSCAN (density-based spatial clustering of applications with noise) method, since this is well-suited to clusters of varying shape, does not require a-priori knowledge about the number of clusters, can handle outliers, and has been successfully applied previously for this purpose [122]. Any outliers not belonging to stay locations are re-classified as move points. In the third (final) step, a time threshold is used to filter very short stays or moves, which is effectively the same as merging move segments or stay events at the same location that are very close together in time.

The algorithm assigns indices to locations without inferring any further information about the nature of the location with the exception of the subject's home. The home location is estimated in two steps: first, the statistical mode of all GPS points is calculated as *home*. Once all *stay* locations are extracted from the dataset, those close to home (within a specified threshold) are classified as being at home. An updated home location is then calculated as the centroid of the subset of all points classified as stays at home.

In summary, the GPS log data (timestamp, latitude, longitude) is used to calculate the following information for each point: whether it is a stay/move; which event it belongs to in a chronologically ordered sequence per day; and for stay points, a location index, and whether it is home. An example trajectory is shown in Figure 10..

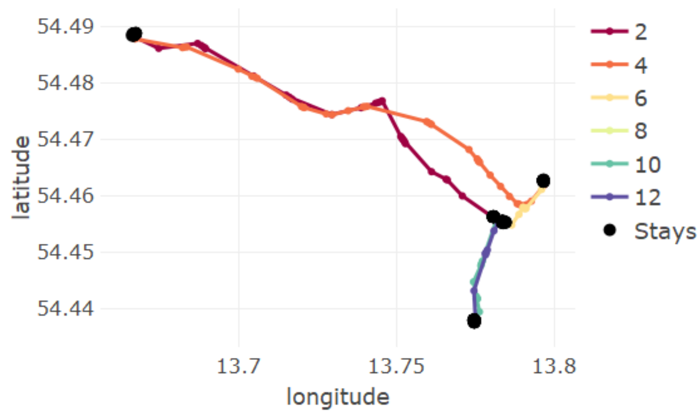

Figure 10. GPS Trajectory showing the sequence of stay/move events. All stays are shown as black discs, and each move event shown as a coloured line named with its chronological order. The "stays" make up trajectory events 1, 3, 5, 7, 9, 11 and 13. (Note: actual GPS data is displaced and map background removed for anonymity).

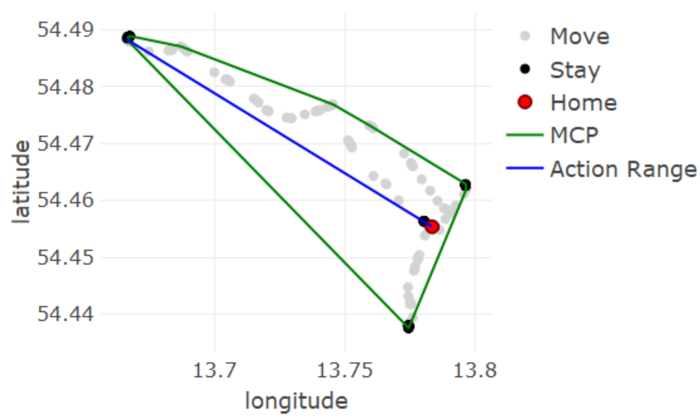

Figure 11. Visual representation of the mobility metrics minimum convex polygon (MCP) and action range, overlaid over GPS data for one subject for a single day (same trajectory as in Figure 10.)

Calculation of mobility metrics:

The set of mobility metrics was selected by combining various other selections used in literature for similar purposes [21], [47], [121], [147], [148], ensuring that different types of measures are included (i.e. spatial, temporal and frequency-based). The set of mobility metrics includes the following calculations:

- *Minimum convex polygon (MCP):* Area of the smallest possible convex polygon constructed around the data, also referred to as the *mobility envelope*. This is calculated by applying the R function `chull` to a subset of points for which the distance to the centroid falls within a 99% quantile.
- *Action range:* Straight-line distance between home and the most distal point of a journey, sometimes referred to as *home range*. The geodesic distance is calculated between the home centroid and all other points in the dataset. For each stay and move event in the GPS trajectory, action range is calculated as the maximum of these distances.
- *Distance covered:* Sum of all geodesic distances between consecutive stays centroids.
- *Time spent out:* Sum of durations for all events excluding stays at home
- *Time spent moving between locations:* Sum of durations for all move events
- *Number of places visited:* Count of unique places visited (including home). This requires location ID's, so that a single place is only counted once even when visited multiple times per day.
- *Number of trips:* Count of all moves in the GPS trajectories

An example of two of the spatial measures, MCP and action range, is shown in Figure 11., where these are calculated for the GPS trajectory in Figure 10.

Activity measurement

Within the context of behavioural monitoring for people with dementia, activity measurement is used to gauge how active a person's everyday life is generally rather than to provide detailed information about physical exercise. Examples of activity measurement in related works (e.g. those investigating mobility and activity among similar target groups) include measurements such as active/walking time, number and duration of walking bouts, and total steps per day [47], [136], [149]. Here we propose extending the measurement of activity bouts beyond walking (or active) to include other modes of transport, since these offer insight into a person's everyday routines/lifestyle, for which any gradual or sudden change could be telling regarding changes in health status. This section describes the methods used to extract these activity features (activity bouts and steps) from sensor data including recognised activities and step count respectively.

Activity bout detection

Activity bouts are detected using data obtained from Google's activity recognition API (ActivityRecognitionClient). This includes the following types of movement: *still*, *tilting*, *on foot*, *walking*, *running*, *on bicycle, in vehicle*, and *unknown*, where *running* and *walking* are both subsets of *on foot*. Each instance of an activity is recorded with a timestamp and confidence level for its recognition. A number of activities can be recorded at the same time instance. The sampling period is irregular but typically ~5 minutes.

The data is first pre-processed to keep only those activities of interest: *still*, *on foot*, *bicycle* and *vehicle*. *On foot* is kept in place of both walking and running in accordance with the target group and purpose. The dataset is then reduced further by keeping only those readings with maximum confidence within each distinct timestamp. Where multiple activity types show equal and maximum confidence, both are included. A time threshold is used to split each activity-type subset into bouts of continuous activity. Occurrences of the same activity type within 10 minutes of one another are grouped into the same bout. The bouts are then summarised yielding the following set of measures: bout number (chronologically ordered per day), activity, start time, end time, duration, and number or readings. In the first development iteration, any bouts with only a single reading where assigned a duration of 5 minutes (based on the mode of sampling periods). Visual inspection of the results showed that this resulted in numerous short bouts coinciding with longer bouts of another activity (e.g. during a longer period of cycling, there may be numerous instances of short walking or vehicle bouts). This led to the decision instead to filter out bouts consisting of only a single reading. An overview of the bout extraction algorithm is provided in Figure 12.

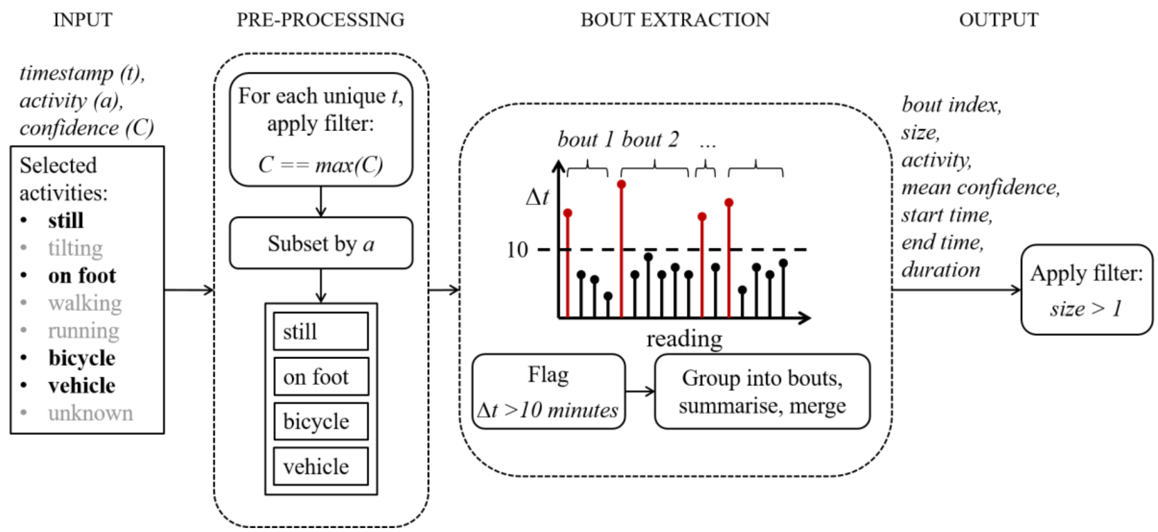

Figure 12. Bout extraction from activity data

Step count

Step count data is used in a straightforward manner to calculate total daily steps. The data is first restructured to obtain a cumulative sum of steps over each day, rather than increasing until the device is restarts/reboots. These signals were examined visually and compared between the two devices, but ultimately used to summarise total steps daily. While step count could potentially be used to measure walking bouts, this was not included, since visual inspection of the data indicated that this would be inappropriate due to erratic update of the step count value. Specifically, longer periods without recordings would result in an incorrect distribution of steps over the day, but without necessarily affecting daily totals. Daily step count from a worn device can potentially account for short, ad-hoc bursts activity (such as performing household chores) that take place over-and-above other exercise regimes or broader movement between geolocations.

4.2.3 Data collection setup: devices, sensors and apps

We have presented a collection of algorithms and metrics to describe individual mobility and activity. Applying these tools to monitor behaviour requires infrastructure to gather the necessary data inputs. In this section, we describe such data collection setup including devices, sensors, and applications. We have sought to compile a setup that can be replicated by others by using off-the-shelf devices and open-source resources as far as possible.

Three types of data are included: location, activity and step count. Location can be recorded using GPS sensors on-board most smartphones and a number of wearables (smartwatches and activity trackers) currently on the market. Recognised activities are calculated primarily from accelerometer data (and in combination with pedometers, gyroscopes and barometers where available). Step count is typically recorded using activity trackers and smartphones, either from on-board pedometers or derived from accelerometer data. The devices used in this study are Google Nexus 5 smartphones and Sony SmartWatch 3 smartwatches, running Android OS v6.0.1. and Android Wear operating systems respectively. Android devices offer unrestrictive platforms for development and have been shown to be comparable to ActiGraph for physical activity estimates [150]. Both devices record location and step count, whereas activity types are recorded on the phone only. A custom-built application was used to securely collect, store and transfer data. The app is an adapted version of that described in [151], which is publicly available under the *OpenSensing* GitHub organization. The app uses Google API's to access sensor data (*LocationListener*, *ActivityRecognitionApi* and *SensorManager*). New users are registered through a web-portal where they create a front-end username and password, and are assigned a back-end pseudonym. The custom app is then accessed from Google Play Store and installed on both paired devices. Watch data is uploaded to the phone, where all data is continuously collected, encrypted and stored locally on the phone. Only when a Wi-Fi connection is available are encrypted data files uploaded to a server over HTTPS. To ensure security, two virtually separate servers are employed: an anonymous raw data server and an identity server with user pseudonyms. Data is then decrypted and transferred to a database for analysis as required by an authorised user (e.g. a researcher with administrator rights). An overview of the data collection setup is provided in Figure 13.

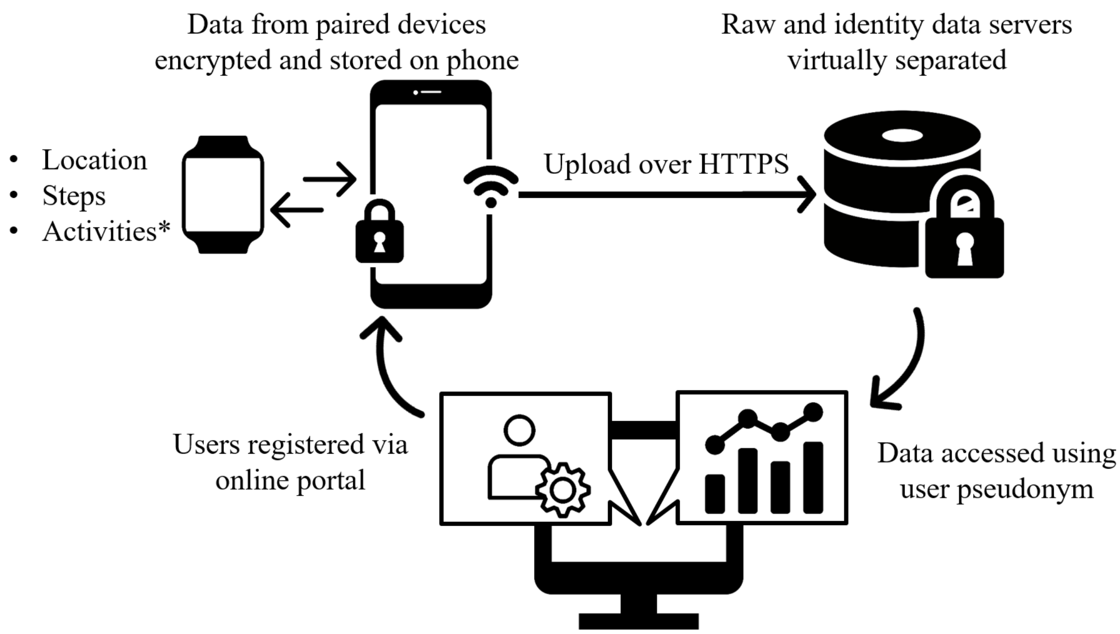

*Figure 13. Data collection setup: data is collected using sensors on-board a smartwatch and smartphone (*activities collected using the phone only), encrypted and stored locally on the phone then transferred securely to a server from where it is accessed by an administrator.*

Through combining the data analysis methods presented in the previous section together with the data collection setup presented here, we provide the necessary tools for a complete behavioural monitoring solution to be applied directly in clinical research and practice. This is evaluated and the results presented in the following sections.

4.2.4 Evaluation

The behavioural monitoring solution was implemented in a pilot feasibility study with five healthy volunteers (3 female, 2 male) between the ages of 31-40. The purpose of the evaluation study was to test the setup under free-living conditions to obtain real world behavioural data with which to examine the performance of the feature extraction algorithms. While the intended target group is ultimately people with dementia, the solution is tested among adults with no cognitive impairment to ensure reliable self-reporting, prior to carrying out any further testing among the target group in future.

Equipment, material and methods

Participants were provided with the behavioural monitoring setup including a smartphone and smartwatch to use for a period of one week. They were instructed to try to wear the watch during the day and charge it at night as required. All participants continued to use their own smartphone during the study and did not interact with the study phone besides taking it with them going from place to place in everyday life, and keeping it charged and paired with the smartwatch. Participants were also provided with a set of log sheets with which to record their movements daily. The log sheets comprised 15-minutes intervals with columns for "stay", "move" and the stay location or mode of travel respectively.

Data analysis

Mobility measurement

Time charts were created to compare participants' logs with algorithm results. Results of the trajectory extraction algorithm were mapped to daily time charts as a signal indicating when the participant was in a *stay* or *move* state. Participants' log sheets were then captured and processed to create matching time charts for their travel trajectories. These were visually assessed to determine the level of agreement between logged and reported travel in terms of both whether trajectory events are detected or not and their timing.

The mobility metrics *time outside of home* and *number of places visited* were calculated using both log sheets and the algorithm results and compared. These metrics were selected because they cover different types of information (time and count) that requires both durations and location identification, and could feasibly be calculated from participant-reported data.

Activity measurement

Automatically extracted activity bouts were plotting on the daily time charts (alongside stay/move signals). Each *move* epoch from the trajectories was annotated with participants' reported transport modes for comparison (see Figure 14.). These combined time charts were visually assessed to gauge the level of agreement between sensor-derived and logged transport modes, identify recurrent errors, and infer strengths or weakness of the approach. Step count data was collected from both the smartwatch and smartphone to compare the two sources in terms of daily totals and cumulative step count signals.

4.2.5 Results

Mobility measurement

Detected trajectories:

Time charts comparing reported and extracted travel trajectories are shown in Figure 14. (one day per participant). Visual assessment of the time charts showed acceptable agreement between the results of the trajectory extraction algorithm and participant logs. Time offsets between the two signals for move start/end times and durations tend to be below 15 minutes, which is the time resolution of the log sheet data. Certain moves are interrupted by a short stay in either one of the signals and not the other, which could be attributed to uncertainty regarding how to fill out log sheets. For example, some participants were not sure whether to log a *stay* when waiting for a bus or stopping briefly during a journey. This is evident in "nasturtium day4" (Figure 14.) where the participant notes a stop during a car journey, and in "agapantha day5" (Figure 14.) where there is a short stay during a multimodal journey. In very few cases, the disagreement between algorithm results and logged data corresponds to longer periods or certain events are missed entirely. An example is shown in "anthurium day3" (Figure 14.) where a 1.5 hour stay is missed. This could be due to a lack of recordings when the participant went indoors. Conversely, certain moves are detected that are not logged, as evident in "nasturtium day4" (Figure 14.). In this particular case, there is a concurrent "on foot" bout, suggesting that the participant may have either forgotten to report a move or moved near their location, e.g. in their garden or for a lunch break at work.

Mobility metrics:

Ultimately, the results of the algorithm for extracting travel trajectories should be sufficient for calculating mobility metrics. This is demonstrated in the comparison between metrics calculated from log sheet and algorithm data (Figure 15. and Figure 16.). Table 6 shows mean daily differences between algorithm and logsheet results per participant over the week. While the algorithm results tend towards lower time out of home than participant's reports, this does not exceed one hour (range between 30 seconds and 55 minutes). Average differences between logged and detected number of unique stay locations per participant did not exceed one location.

Figure 14. Time charts comparing log sheets and algorithm results for trajectory extraction and activity bout detection. A single day from each participant is shown.

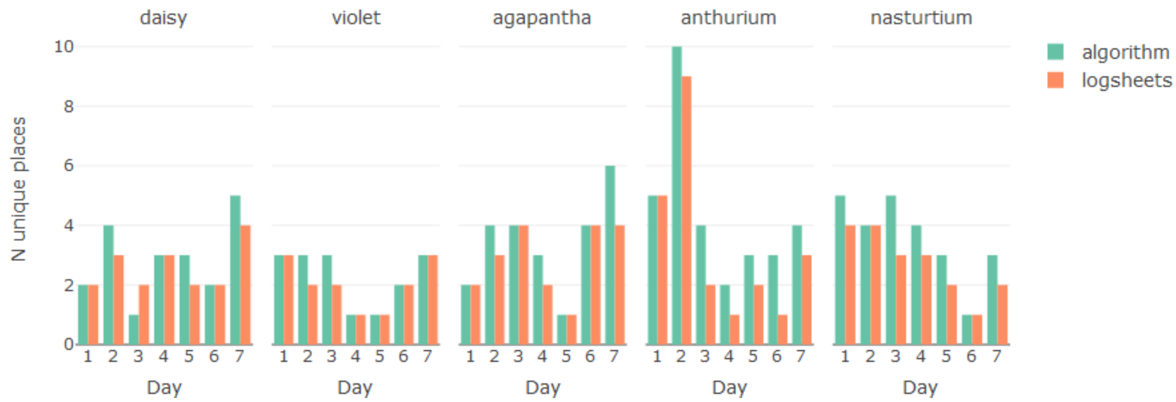

Figure 15. Comparison between the numbers of unique places detected from sensor data and reported by study participants in logsheets.

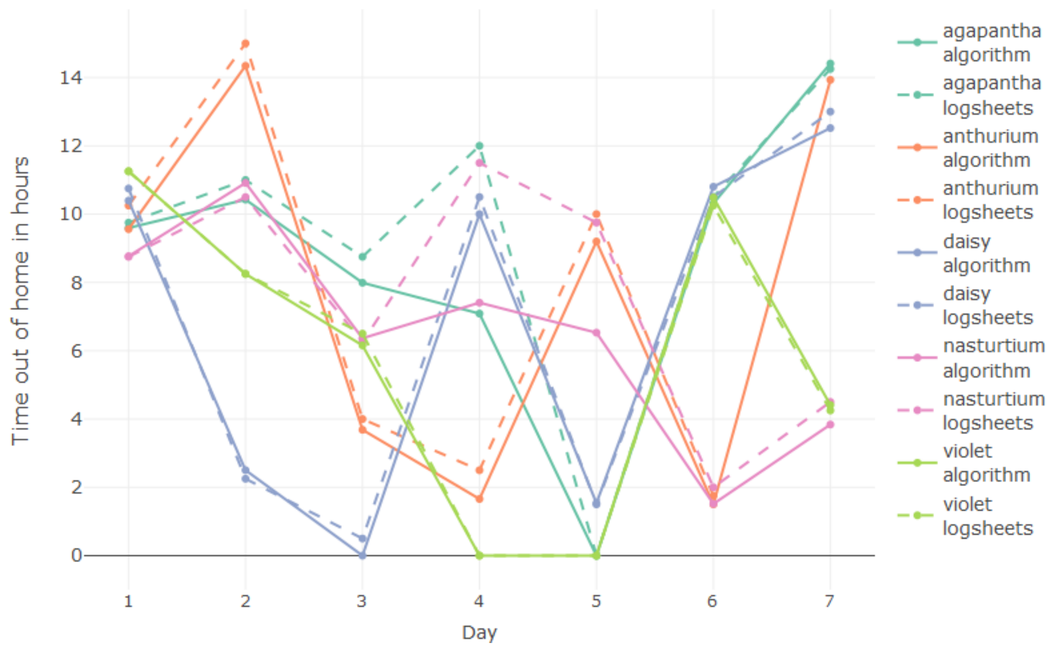

Figure 16. Comparison between the time spent out of home detected from sensor data and reported by study participants in logsheets.

Table 6. Mean differences between algorithm and logsheet results over the week for daily total time spent out of home (Tout) and unique stay locations per participant. Positive results indicate algorithm > logsheets and vice versa

Participant code	Mean diff. Tout (minutes/day)	Mean diff. locations (count/day)
agapantha	-55.11	0.57
anthurium	-35.53	1.14
daisy	-10.67	0.29
nasturtium	-67.86	0.86
violet	0.50	0.29

Activity Measurement

Activity bout detection:

The detected activity bouts were plotted together with trajectories in the time charts and compared with reported transport modes. Visual assessment showed that the algorithm generally detects activity bouts during moves and is able to detect multimodal travel. There are, however, limited examples where no bouts are detected during reported travel (e.g. walks reported in "anthurium day3", Figure 14.).

One evident limitation is that the detected activity bouts tend not to fill the entire duration of the travel. Instead, each journey comprises one or more shorter bouts along with still periods and gaps in the signal. In some (but not all) cases, this may be an accurate representation of travel comprising multiple stops (e.g. when changing from one mode of transport to another).

Accuracy of the detected transport mode is rooted in the activity recognition, which is not developed and tested within this work, yet important to consider none-the-less, partly because the activity recognition accuracy influences decisions regarding how this data input should be processed. One recurring error was confusion between travel by bicycle and by vehicle, which is evident in "daisy day1" (Figure 14.).

An interesting observation is the lack of walking bouts during *stays*, which may be expected as part of an ordinary workday. One contributor may be filtering of single-reading bouts, however this presents an apparent trade-off between detecting more actual activity bouts and introducing additional, incorrect activities during others. Another likely cause is that the data is collected from the smartphone, which may not have been carried on the participant's person for shorter walking trips around the home or workplace, highlighting the importance of investigation within real-life settings. This is examined more closely in the step count data, which is available for both phone and watch.

Step count:

Step count is compared between the watch and phone for all days where both sources are available. Due to technical issues encountered accessing the watch data, this is available for selected participant-days only (agapantha = 4, anthurium = 5, daisy = 0, nasturtium = 7, violet = 3). The comparison shown in Figure 18. demonstrates that the watch records vastly more steps than the phone. The cause of the disparity between counts appears to be twofold. There are periods where only the watch step count increases and not the phone (Figure 17., violet day8), indicating that the watch may be worn while the phone is placed still. Then there are periods where both increase simultaneously, but with steeper increments on the watch than on the phone (Figure 17., anthurium day7), indicating that when both are used, the watch counts more steps than the phone.

Visual inspection of the step count data revealed a limitation regarding sampling irregularities. Long periods (over an hour) without any readings are common in the watch step count (Figure 17., anthurium day8). While the steps appear to be logged during these periods (and therefore not expected to influence daily total step counts), this does not support bout detection from the step count data, since it is impossible to infer the distribution of walking bouts over the course of the day.

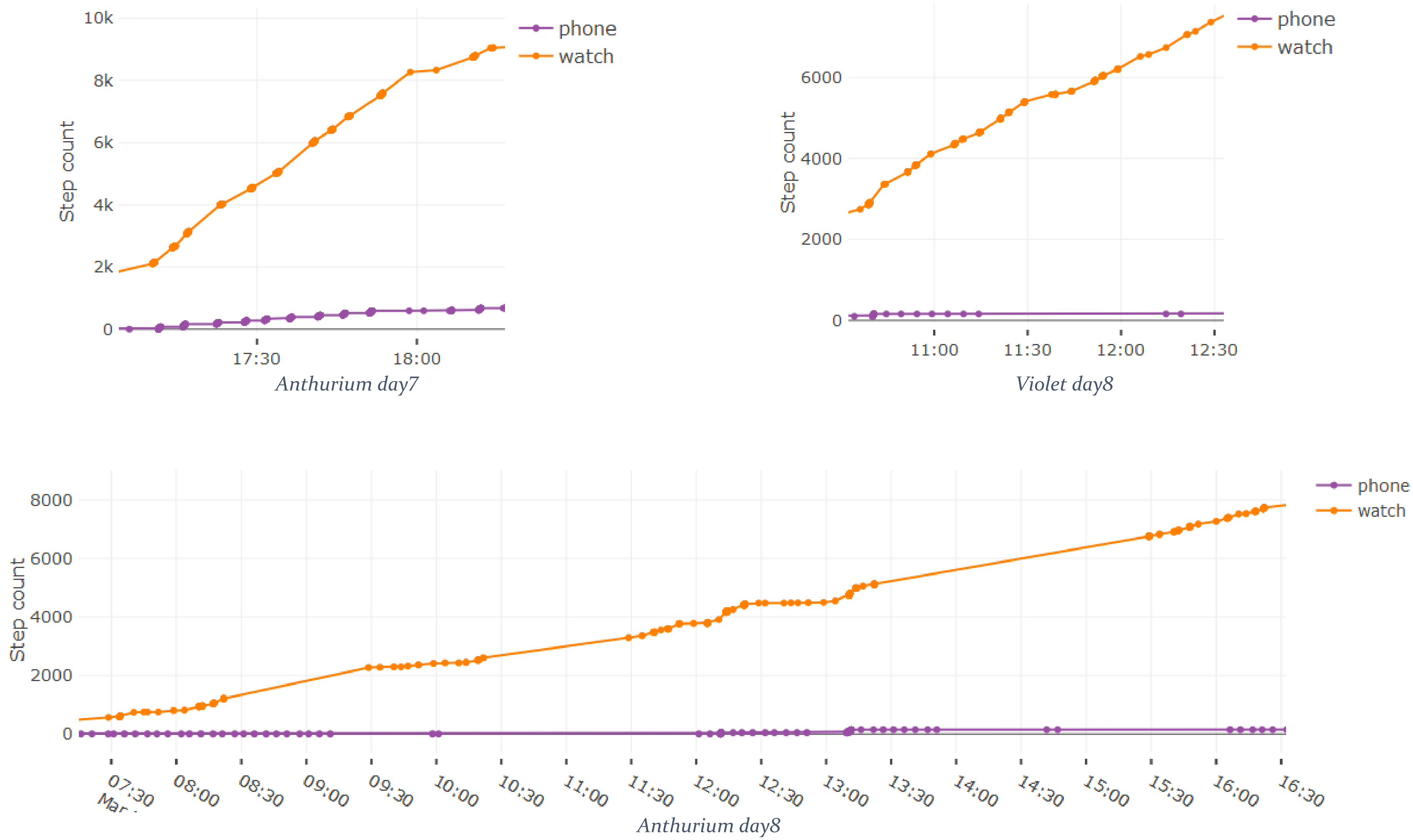

Figure 17. Comparison of step count cumulated over the day between watch and phone

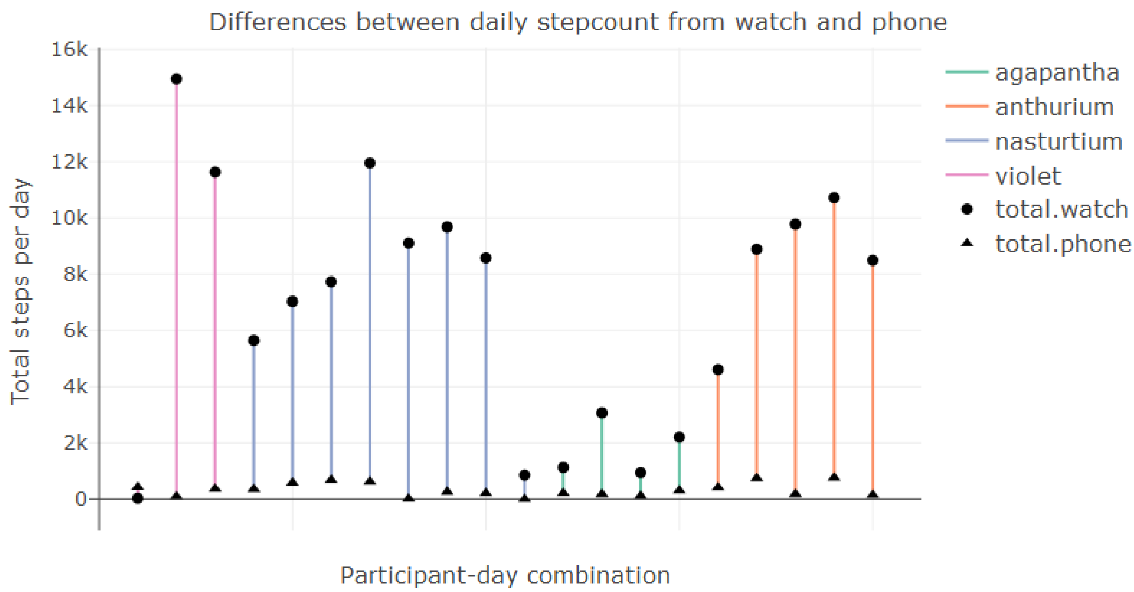

Figure 18. Error bars demonstrating the large difference between total daily step count between watch and phone for each available day

4.2.6 Discussion

Principal findings

This study has presented a behavioural monitoring solution that leverages widely available data (location, activity, step count) from mobile and wearable devices used in everyday life. A set of tools was developed to measure mobility and activity, and a generic data collection setup described to support its implementation. Evaluation of the behavioural monitoring solution showed that it is capable of estimating participants' travel trajectories from raw GPS data to calculate spatial, temporal and count-based mobility metrics. An activity-bout detection algorithm was shown to successfully extract bouts of activity during travel including for multimodal transport, however does not capture the full duration of daily activities. Step count was shown to be more reliable from a wearable device than from a smartphone under real world conditions, in which case it is preferable over activity bouts for estimating general daily activity including during stays such as at work or home.

Transferability

An important goal of this work has been to describe a solution that be replicated by others for monitoring behaviour to support clinical research and practice in a range of applications. Here we discuss the extent to which the setup is transferable in terms of both technical aspects and clinical utility.

A core contribution of this work is the set of algorithms compiled and developed to translate sensor data into meaningful behavioural insights. For these to be transferable, we consider what data is required as inputs and how this is acquired. For the mobility monitoring, raw GPS data is sufficient. While additional information about location accuracy is used to filter the data, this is not mandatory (however, it is recommended that the accuracy does not greatly exceed the span of a typical stay location). The sampling frequency does not need to be regular, however at least one recordings should be available approximately every 5 minutes for substantial sections of the period of interest (this is based on the time thresholds used to extract stays and moves, which can also be adjusted). The activity bout detection relies on recognised activities rather than raw data from movement sensors, and as such, may require additional processing where this is unavailable. Step count data is processed very minimally and used only for daily totals and not bout detection due to sparsity in the count updates. This can therefore can be easily replicated using another data source, however based our findings comparing the watch and phone, a wearable device is recommended. This can be summarised in the following requirements:

- *For mobility measurement:* GPS data with an accuracy of up to ~30 meters and sampling periods of up to ~5 minutes (not necessarily regular, and gaps allowed).
- *For activity measurement:* recognised activities with sampling intervals lower than the threshold used for bout detection, and step count data from a wearable device updated at least once per day.

Where any of the required data is unavailable or not of interest, other modules can be applied independently. Regarding devices and data collection, we have used devices running Android and Google API's to access the sensor data these generate. This can be replicated using any Android device with the same sensors. The infrastructure for storing and accessing data is based on open source software from the OpenSensing GitHub organization described in [151]. For Apple products, a similar approach could be feasibly be implemented using frameworks such as Apple Research Kit.

In terms of clinical utility, we now consider characteristics of target groups for whom the behavioural monitoring solution is suitable. The mobility monitoring functionality is capable of monitoring out-of-home mobility only, which can be interpreted as beyond 25 meters from home (based on the accuracy threshold applied). This excludes only patient groups whose mobility levels are at the lowest end of the spectrum, described in terms of movement from a bedroom to other rooms in their place of residence. The activity monitoring functionality can be used to gain insight into how a person travels around and to estimate total daily steps as an indicator of how active their day is. This does not provide detailed information about physical activity intensity or precise activity bout durations. This excludes sports not carried out on foot. The activity monitoring is therefore best suited to monitoring everyday life habits rather than, say, exercise programmes. For example, the activity monitoring would include movement about the home to carry out light household work, around the workplace to meet colleagues or take breaks, and movement between locations throughout the day. Based on these characteristics regarding both mobility and activity, suitable target groups could include older adults who live in the community. Of particular relevance are cognitively impaired individuals for whom self-reporting can be a challenge. The setup may also be relevant for monitoring mental illness patients for whom mobility- and activity-related behaviour is highly meaningful, as well as those suffering from (or at high risk of) chronic illnesses where lifestyle factors play a prominent role, but are neither home-bound nor extremely physically active.

Implications for clinical research and practice

The transferability and modular structure of the behavioural monitoring approach presented offers far-reaching potential to support clinical research and practice. This could be to evaluate the effect of treatment on behaviour in intervention studies targeting relevant patient groups, or to advance our understanding of how different factors or conditions are associated with changes in behaviour.

The behavioural monitoring solution could support interventions that rely on, or could benefit from, information about lifestyle and behaviour. This includes use-cases such as:

- cognitive rehabilitation for people with dementia, where patients are supported in creating structured daily routines and engaging in activities
- active aging interventions aimed at improving quality of life and independence among the elderly
- drug therapy where dose should be adjusted to minimise side effects that impact mobility and activity
- interventions aimed at activating people affected by depression
- goal-oriented interventions to improve quality of life, e.g. to track specific mobility- or activity-related goals

By relying on common, personal devices and allowing for real-world data, the behavioural monitoring solution is geared to enable P4 healthcare approaches by generating information within the scale and context that this requires. Continuous behavioural monitoring in a natural home setting can reveal patterns in behaviour and fuel the development of predictive models to anticipate disease trajectories or adverse events. This also allows healthcare professionals to proactively prevent problems earlier than would be possible with pre-scheduled visits months apart. Knowledge about behaviour and lifestyle can inform personalised interventions that take into account which aspects of quality of life are most important to the individual. Data describing behavioural patterns also offer a valuable resource for sharing information about patient status between patients and healthcare providers in participatory care approaches.

4.2.7 Conclusion

This work has described a novel sensor-based approach to behavioural monitoring for use among people with dementia. We have compiled, adapted and developed a set of algorithms to measure mobility and activity from sensor data including location, recognised activity and step count data, and present and test a technical setup for collecting these data inputs.

An evaluation of the behavioural monitoring solution among five participants for one week showed that the setup was capable of extracting travel trajectories, mobility features, activity bouts and daily step count using a smartphone and smartwatch in a natural setting. Each set of results provides related yet distinct information about a person's daily life: mobility describes the extent to which the persons goes out, activity bouts describe *how* they go out, and step count supplements this with information about how active they are generally including periods at home or work. Combining these measures provides insights into daily rhythms or longer temporal patterns. This could support clinical applications involving patient groups for whom mobility and activity behaviour is closely tied to intervention outcomes, such as among the elderly and people with dementia, and to advance predictive, preventative, personalised and participatory (P4) healthcare.

4.2.8 Abbreviations

API: Application programming interface

GPS: Global positioning system

P4: Predictive, preventive, personalised and participatory

MCP: Minimum convex polygon

DBSCAN: Density-based spatial clustering of applications with noise

References

Article references are merged with thesis references for document continuity. Reference numbering in this section is therefore adapted from the original publication.

Chapter 4 conclusions

This chapter has described the development of a technological solution for support and monitoring among people with dementia comprising smart, mobile and wearable technology. The development steps described include the selection of devices and applications for support in everyday life, development of the infrastructure required to access sensor data from the devices, and development of algorithms for monitoring behaviour through activity and mobility measurement.

Testing the selected devices and applications among users to analyse user acceptance helped to deepen an understanding of how appropriate existing tools are for supporting people with dementia in terms of both usability and usefulness. This has informed the approach for offering such support in this project by indicating which applications were more useful and usable and thus could be offered generically (e.g. calendar/reminder tools), and which require more effort and thus should be carefully selected only according individual need and ability (e.g. navigations support). Development and pilot testing of the behavioural monitoring solution among healthy users who simultaneously logged their movements demonstrated that this successfully extracts features from location, recognised activity and step-count data to describe out-of-home mobility and activity.

In the following chapter, the support and monitoring functionality developed in this thesis is combined and implemented among people with dementia to evaluate its feasibility for use in rehabilitation interventions.

Chapter 5

EVALUATE

Objective 3: Evaluate through clinical implementation of the technological solution its feasibility in terms of supporting patient quality of life and informing care

The previous chapter has described the development of a technological solution to be implemented in rehabilitation interventions for people with dementia. This comprises a smartphone and smartwatch housing activity and location sensors, and capable of providing support through a wide range of applications. It also includes infrastructure for accessing data from device sensors and a set of algorithms to translate this into behavioural measures.

In this chapter, Chapter 5, we move from development to evaluation. Section 5.2 is a journal article (submitted to JMIR [20]) describing a feasibility study in which the technological solution is implemented in a real-life context among people with dementia in six in-depth, longitudinal case studies, the main contribution of this chapter. Preceding the article are notes on clinical perspectives from a preliminary evaluation that took place during the development phase. Through these two sections, we involve multiple perspectives from the dementia care network and present detailed findings regarding the potential for the technology created in the previous chapter, to support dementia care processes, specifically providing support and monitoring functionality in a rehabilitation context.

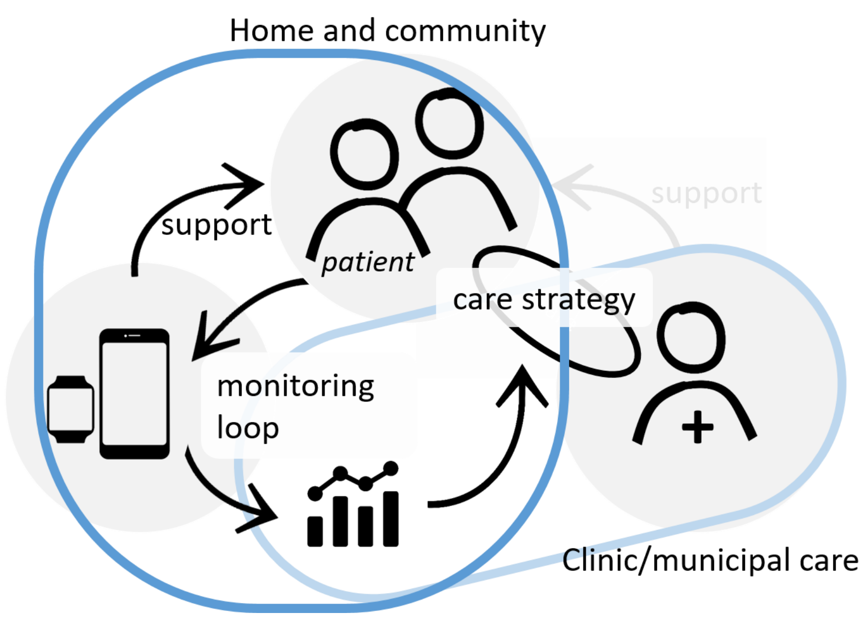

Figure 19. System viewpoints employed in this chapter. Section 5.1 (lighter blue) focuses on sensor-based measures informing care, and section 5.2 (darker blue) on support and monitoring roles of technology for the patient in their home/community environment.

5.1 Preliminary evaluation: notes on clinical perspectives

An early evaluation step was carried out during the development phase to gauge healthcare professionals' perspectives on the clinical relevance of measures derived from activity and location data. This was conducted together with a master's student as part of his thesis project [152]. A workshop was held on communicating eHealth information with the healthcare professionals at the dementia and memory clinic to collect feedback on clinical relevance of several behavioural measures, including:

- daily activity in minutes per day
- area covered per day, including an indication of "normal" to show whether this is higher or lower than expected
- daily cycle, showing the period between when user gets up in the morning to going to bed at night
- daily overview, represented by four activity types as percentages of a 24-hour cycle: sleep, active, sedentary (all at home) and periods out of the home

The workshop included eight participants from the dementia and memory clinic at Rigshospitalet-Glostrup, comprising three specialist doctors and five nurses. Participants were oriented on the information to be presented, since participants had limited knowledge of the possibilities of what might be measured from mobile/wearable sensors. Participants were presented with a series of visualisations and asked what information it showed, whether this would be valuable to their work and why or why not, and what further data they would add.

Overall, the information presented was perceived as clinically relevant, however certain visualisations were poorly understood, and as such influenced the evaluation of clinical relevance, and a number of concerns were also raised. Noteworthy findings are summarised as follows:

- Physical activity levels were viewed as useful indictor of health and function, with one participant responding that: *"This information would be of interest as it would document levels of activity and this could be used by us to see a sign of sickness - so definitely yes, it is useful."*
- Using a single measure of mobility, in this case as *daily area covered*, was criticised as not being informative enough on the details of the mobility behaviour. For example, a participant asked: *"What happens if a PWD is walking 100km's in circles… that would not tell*

us anything?" This motivates including multiple measures to qualify *area coverage* with information such as how many trips or how far from home the person travels.

- Certain comments on the activity plots in fact indicate that information about mobility would be relevant, e.g.: *"I like that you can see whether a patient is becoming more and more confined to their bed."*
- Trends in behaviour were of greater interest than actual levels
- Combinations of different measures were of interest, such that participants could relate the various behaviours.
- Two main concerns emerged:
    - Data validity, e.g. not knowing whether "sleep" was really sleep or just when they were not wearing the smartwatch
    - Lack of detailed explanation behind information about behavioural change, e.g. if activity is low, why is this the case? Noting that this would necessitate a call to a caregiver to determine the cause of change in behaviour. One participant comments that: *"I need to know precisely what this sedentary behaviour covers. It doesn't show at all if they are lying awake feeling lonely or scared - therefore it is limited information."*

The workshop findings suggest that the behavioural measurement opportunities presented by the setup described in [17] (Section 4.2) would provide valuable information about patients' health and function in everyday life. The concerns raised about requiring detailed information are valid and are addressed through positioning the technology in a wider care process and defining its role. For example, this could mean that information derived from behavioural measures should trigger further investigation or action rather than providing conclusive results for, say, diagnostic decisions.

The workshop took place in the period between identifying a measures of interest from literature (section 3.3, published in [21]) and developing algorithms to calculate these (section 4.2, published in [17]). It therefore served to validate the clinical relevance of activity and mobility for behavioural monitoring rather than the actual sensor data or algorithm results.

The following section presents a journal article resulting from research undertaken as part of this thesis [20] documenting an evaluation study in which the complete technical setup – including behavioural monitoring and support – are implemented in practice in a real-life context.

5.2 Evaluation in the AWEAR feasibility study

The AWEAR (Adapting wearable technology) feasibility study comprises six case studies used to evaluate the mobile/wearable technology based solution for support and monitoring developed in Chapter 4 among people with dementia in a real life context. The article forming this section describes the study focusing on analysis methods and findings. Additionally, a set of appendices is provided with this thesis that provide further insight into the research process. These include:

- Information provided to participants introducing the study, as published on the Copenhagen Centre for Health Technology (CACHET) website (Appendix F)
- A user manual provided to participants as a resource to aid them in operating the smartphone and smartwatch used in the studies (Appendix G)
- Timelines for each participant showing documented interactions with the research team (Appendix H)
- An HTML notebook created to evaluate incoming data and identify any possible technical issues (Appendix I)

Other relevant appendices include an overview of the custom applications used to collect device data (Appendix D) and an overview of the code structure for behavioural algorithms (Appendix E).The remainder of this section has been published in *JMIR Preprints* while under review for publication in *Journal of Medical Internet Research* [20].

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Adapting mobile and wearable technology to provide support and monitoring in rehabilitation for dementia: a feasibility study
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URL: https://preprints.jmir.org/preprint/12346

Adapting mobile and wearable technology to provide support and monitoring in rehabilitation for dementia: a feasibility study

Abstract:

Background: Mobile and wearable devices are increasingly being used to support our everyday lives and track our behaviour, which are two core components of cognitive rehabilitation. Personal devices could therefore be employed in rehabilitation approaches aimed at improving independence and engagement among people with dementia.

Objective: The aim of this work is to investigate the feasibility of using smartphones and smartwatches to augment rehabilitation by providing adaptable, personalised support and objective, continuous measures of mobility and activity behaviour.

Methods: A feasibility study comprising six in-depth case studies was carried out among people with early-stage dementia and their caregivers. Participants used a smartphone and smartwatch for 8 weeks for personalised support and followed goals for quality of life. Data was collected from device sensors and logs, mobile self-reports, assessments, weekly phone calls and interviews. This was analysed to evaluate the utility of sensor data generated by devices used by people with dementia in an everyday life context, to compare objective measures with subjective reports of mobility and activity, and to examine technology acceptance focusing on usefulness and health efficacy.

Results: Adequate sensor data was generated to reveal behavioural patterns even for minimal device-use. Objective mobility and activity measures reflect fluctuations in participants' self-reported behaviour, especially when combined, may be advantageous in revealing gradual trends, and provide detailed insights regarding goal attainment ratings. Personalised support benefitted all participants to varying degrees by addressing functional, memory, safety and psychosocial needs. Four of six participants felt motivation to be active by tracking their step count. One participant described highly positive impact on mobility, anxiety, mood and caregiver burden mainly as a result of navigation support and location tracking tools.

Conclusions: Smartphones and wearables could provide beneficial and pervasive support and monitoring for rehabilitation among people with dementia. These results substantiate the need for further investigation on a larger scale, especially considering the inevitable presence of mobile/wearable technology in our everyday lives for years to come.

Keywords: *dementia, cognitive rehabilitation, mobility, activity, mHealth, uHealth, pervasive healthcare, P4 healthcare, healthcare design*

5.2.1 Introduction

New approaches are needed to respond to the growing dementia challenge as the population ages [54]. A global action plan recently issued by the World Health Organisation calls for solutions to improve the lives of people with dementia and their caregivers, and to reduce the impact the condition has on communities [13]. One promising approach is through rehabilitation, defined as a problem-solving process aimed at optimising social participation and well-being. Rehabilitation among people with cognitive impairment, or cognitive rehabilitation, is characterised by a personalised, collaborative approach to setting and working towards individual goals within an everyday life context [15]. Two core components of rehabilitation interventions are support and assessment to inform further care strategy iterations [57]. Rapid advancement in mobile and wearable technology are presenting exciting opportunities for widely available, personal devices to fulfil such purposes, which are as-of-yet not being realised in practice.

This work investigates how smartphones and smartwatches might be applied for rehabilitation among people with dementia by offering both personalised support in everyday life and objective, continuous monitoring of mobility and activity to assess function and engagement.

Various forms of information and communication technology (ICT) have been used for people with dementia to provide functional support in everyday life, improve safety, target psychosocial needs, and supporting caregivers [153], [154]. Personal devices such as smartphones and wearables offer a convenient and familiar platform through which to offer similar support. A host of existing tools for communication, scheduling, reminders, navigation, social and leisure purposes are already available from off-the-shelf applications. An increasing proportion of elderly people will rely on such tools prior to dementia onset as current users' age. Already today, many people with mild cognitive impairment and dementia are using ICT [155], and studies have described interest among members of this population in using wearables for support [156]. Mobile and wearable devices are also packed with sensors that can be used to gather information about users' lifestyle and behaviour, such as their mobility and activity levels or patterns. Monitoring behaviour among people with dementia can provide valuable indicators for functional performance and wellbeing to inform care strategies [157], and thereby support the rehabilitation process.

Mobile technology has successfully been applied to fulfil various functions related to rehabilitation among people with dementia or other neurological diagnoses, such as providing memory support following traumatic brain injury [60], monitoring activity and mobility [49], [141] and goal setting

[158], and for rehabilitation after stroke [159]. We build upon this work by extending and combining support and monitoring functionality offered by mobile devices, and by implementing this among people with dementia in a series of in-depth case studies. The primary aim of this work is therefore to evaluate the feasibility of using mobile and wearable technology to support rehabilitation for dementia. We have implemented a technological setup combining both personalised support and behavioural monitoring among people with dementia in a real-life context in a series of six in-depth case studies to address three main objectives:

1. Examine the technical feasibility of sensor-based behavioural measurement using smartphones and smartwatches among people with dementia
2. Compare participants' subjective perceptions of their behaviour with objective, sensor-derived measures
3. Evaluate user acceptance focusing on usefulness and health efficacy

Through fulfilling these objectives, this work contributes with new evidence on the potential for smartphones and wearables to benefit rehabilitation in practice, identifying areas for further research on a larger scale. Addressing new opportunities presented by mobile devices and the data these generate makes an important step towards the wider vision of data-driven healthcare interventions that enable predictive, preventative, personalised and participatory (P4) healthcare.

5.2.2 Methods

Recruitment

Recruitment was carried out through the dementia and memory clinic at a Danish hospital. The population of interest is community-dwelling adults in the early stages of dementia, which includes people with mild-to-moderate cognitive impairment. Participants were required to live with their primary caregiver, due to the supportive role the caregiver plays in the study (e.g. providing information). Participants were not required to have any prior experience using smart technology. Exclusion criteria included disability that would either affect the participant's ability to use smart technology (e.g. severe vision, hearing loss or apraxia), or extremely limited mobility and activity levels (e.g. home- or bed-bound).

Study design

A longitudinal study design comprising multiple case studies was employed. Each case includes both a main participant (person with dementia) and their caregiver over a period of at least 8 weeks.

During the study, participants used smart devices for support in everyday life, answered daily reports on their mobility and activity levels, and followed an individual goal. Behavioural data was recorded from device sensors throughout participation. The study procedure is outlined in Figure 20, which shows the series of participant-interactions through which both quantitative and qualitative data was collected throughout the process.

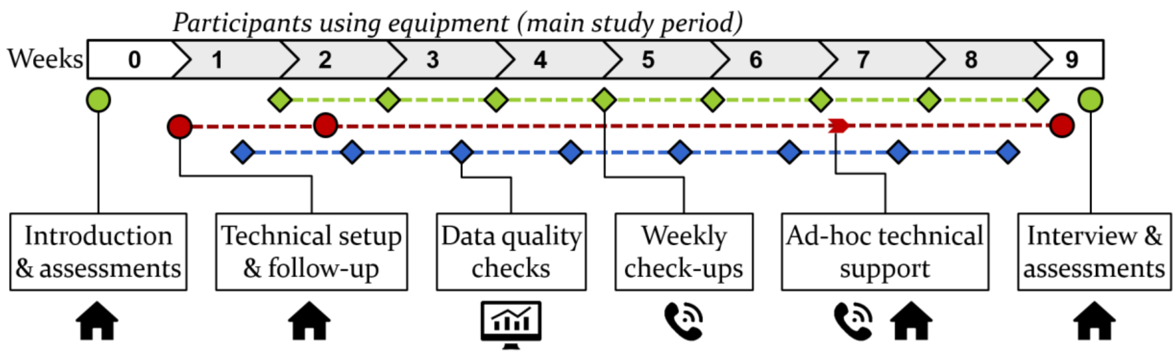

Figure 20. Procedure for each case study showing interaction points and data collection

Technical setup for support and monitoring

The technological setup comprised a smartphone (Nexus 5 running Android OS v6.0.1.) paired with a smartwatch (Sony SmartWatch 3 running Android Wear), a mobile self-reporting module, and an application for secure collection of sensor data and logs from the devices. A detailed description of the system is available in [17].

The devices were intended to support participants in their everyday lives. A technical orientation meeting was held at the start of each case study to introduce the devices and set them up in collaboration with the participant and their caregiver. A standard setup was adapted to fit each participant according to which settings or applications they already used (where applicable), and to include additional functionality (apps, settings) selected to support their individual needs.

As a standard setup, the smartphone home screen displayed the time, upcoming appointments, and based on interest from all participants, a daily step count. All participants were provided with Google Calendar and shown how this could be used to remember tasks or appointments, since this was shown to be useful and not too challenging for participants in an earlier study [1]. A follow-up visit one week after orientation was carried out to resolve initial issues and repeat instructions. Participants were also provided with an illustrated manual and offered technical support throughout the study over the phone and in home visits as required.

In addition to providing support, the devices were used to collect behavioural data. Sensor data including location, activity types and step count, was recorded continuously to calculate a range of mobility and activity measures. Mobile self-reports were used to collect participants own perceptions of their daily mobility and activity levels relative to their own usual levels.

Goal setting and following

Participants set individual goals that they followed throughout participation. Goals were defined together with a member of the research team (trained in psychology). The goals were related to quality of life specifically within the themes of mobility and activity, and according to participants' own views of what was important to their lifestyle. Goal definition was performed directly after mobility and activity baseline assessments to frame the discussion on related goals. Where necessary, this was guided by examples such as getting out of the house regularly, making appointments, target activity levels or performing certain activity types. Participants were asked to evaluate their own goal attainment in weekly phone calls, which provided an opportunity for them to qualify their answers with further information. Goal attainment was scored following the approach described in [160] along a range from -2 to 2, whereby a score of 0 is assigned if the goal is met, with 2 levels in either direction for under- or over-achievement.

Data collection

Quantitative and qualitative data were collected throughout the studies, as outlined in Table 7 and in Figure 20 showing the protocol steps. Background information was collected at study start along with cognitive impairment test results from their latest visit to the clinic. A set of questionnaire-based assessments were performed at participation start and end. These are collected as a reference for participants' profiles and in case of marked change that may influence the participant's experiences, and not used for pre/post analyses since these are not included the study design. Assessments included for quality of life, functional in daily living activities, caregiver burden, mobility and activity (see Table 7). Mobility and activity questionnaires were adapted to fit the study purposes. The life-space assessment used to measure mobility [161] includes questions about distance ranges travelled from home with information about frequency (days per week) and level independence (independently, help from equipment, help from others), of which we exclude the latter and calculate scores assuming independence. The physical activity questionnaire [162] in its original form asks about moderate and vigorous activity at work, for leisure and for transport to calculate weekly totals in minutes, and about sedentary periods. Sections were selected and simplified to exclude distinguishing between moderate and vigorous, resulting in a weekly total of active time only.

Data from device sensors and logs was collected throughout participation, and mobile self-reports were issued daily. Participants evaluated their own goal attainment weekly over the phone. A semi-structured interview with each participant at study end was used to gather qualitative data on their experiences particularly in relation to technology acceptance factors.

Table 7. Summary of data collected in the case studies

Category	**Frequency**	**Description**
Background information	At start	Demographic: age, gender, education, occupation
		Cognitive impairment severity (MMSE, ASE)
Questionnaires	Start/end	Quality of life (QOL-AD)
		Functional performance (FAQ-IADL)
		Caregiver burden (ZBI, short form)
		Mobility (LSA, adapted)
		Activity (GPAQ, adapted)
Device data	Continuous	Location
		Activity
		Step count
		Battery status
		Screen on/off
Mobile self-reports	Daily (evening)	Perceived mobility (daily)
		Perceived activity level (daily)
Meetings and interviews	Weekly	Phone-calls: perceived goal attainment score, and supplementary notes
	Study end	Semi-structured interview on experiences and outcomes
	Ad-hoc	Support interactions

Data analysis

Three main analyses were performed to fulfil the study objectives. The first examines the availability and utility of the data generated by the smart devices, the second examines agreement between participants' subjective reports of their behaviour and objective, sensor-based measures, and the third examines user acceptance factors.

Analysis 1: Data availability and utility

The aim of this analysis is to determine whether the smart devices, as used in a real-life context, generate adequate data for the intended purpose of monitoring behaviour. This depends both on the technology functioning correctly and on the participants using them sufficiently, i.e. keeping the devices charged and connected, carrying them around with them, and answering mobile self-reports. We examine:

- *Data availability:* the proportion of the study period for which data is available from each of the devices and from the mobile self-reports.
- *Data utility:* visual inspection of the device-interaction and behavioural data to evaluate whether data quality and quantity is sufficient for behavioural patterns to be evident

Analysis 2: Self-reported vs sensor-based measurement of behaviour

The aim of this analysis is to determine whether the behavioural insights gained from sensor data agree with participants' own perceptions of their behaviour. Identifying where these differ can guide further investigation into whether this is due to inaccurate perceptions or technical failures. Since current rehabilitation approaches rely heavily on input from participants and caregivers to assess progress/outcomes, it is also relevant to investigate how such subjective reports differ from the proposed sensor-based approach. Sensor-derived measures are compared with participants' mobile self-reports of activity and mobility levels and their weekly goal attainment ratings.

The data for this analysis includes a set of mobility and activity features that are derived from the sensor data (location, recognised activities and step count) using a collection of algorithms described in detail in [17]. Location data merged from the phone and watch is first used to extract a series of *stays* and *moves* throughout each day. These, together with the raw GPS coordinates, are then used to calculate a set of spatial, temporal and frequency-based mobility measures including:

- *minimum convex polygon (MCP)* or *mobility envelope* (area of the polygon constructed around location data)
- *action range* or *home range* (furthest straight-line distance travelled)
- total distance covered (out of home only)
- time spent out of home
- time spent moving between locations
- number of places visited
- number of trips

Recognised activities (accessed using Google's activity recognition API, from the phone only) are used to extract bouts of activity within the categories: *still*, *on foot*, *bicycle* and *vehicle*. Daily total steps are recorded independently from the phone and watch. This data is used to calculate the following activity measures:

- Active time: sum of durations of all activity bouts on foot and bicycle
- Active bouts: total count of all activity bouts on foot and bicycle
- Still time: sum of duration of still bouts
- Total steps

The mobile self-reports are answered in terms of the day's level relative to normal on a five-point scale as: *much less than normal*, *less than normal*, *normal*, *more than normal*, or *much more than normal*. These are recorded as values within the set {0, 0.25, 0.5, 0.75, 1}, where 0.5 equates to *normal* for interpretation as a median. For comparison with self-report answers, the sensor-based measures are ranked as percentiles using the empirical cumulative distribution function. The self-reported and sensor-based measures are compared visually to evaluate their correlation over the study period for each participant.

The comparison between perceived goal attainment and sensor-based measures requires individual analysis according to each participant's defined goals. In most cases, this involves selecting relevant activity and/or mobility measures and aggregating these by week. Other methods included detecting visits to a specified location (e.g. a training centre), which requires a priori knowledge of the location's GPS coordinates to be supplied by the participant concerned. Goal attainment ratings were collected during weekly phone calls and scored across a range from -2 to 2, where 0 corresponds to having met the goal and with 2 levels for over- or under- achievement in either direction. The sensor-based measures are ranked as percentiles as in the comparison with mobile self-reports, only for this analysis these are shifted by 0.5 such that the median lies on the zero line for comparison with goal attainment ratings.

Analysis 3. Qualitative analysis of user acceptance - usefulness and health efficacy

The aim of this third analysis was to evaluate potential acceptance of the devices for support. Usability and usefulness are two important factors influencing technology acceptance, as proposed in the technology adoption model and numerous adaptations thereof [163]. We are interested in whether participants benefit from support selected from a broad range of available tools, therefore usefulness is more appropriate than usability (which is evaluated for a similar smartphone and smartwatch setup among the population of interest in [1]). For healthcare technology specifically, health efficacy is an important consideration [19]. This analysis therefore focuses on usefulness and health efficacy in terms of impact on aspects of quality of life such as function in everyday life and social engagement.

Data is collected using semi-structured interviews carried out with the person with dementia and their caregiver at the end of each case study, including questions on:

- pre-existing tools and coping strategies
- experiences using the technology, including: how it was used, for which purposes, difficulties, benefits
- adequacy of the technical support and their own knowledge and skills for operating the devices
- expectations and whether these were met, which needs were not met, and any desired (but absent) functionality
- impact on their everyday life and on their health

Notes from the weekly phone calls as well as technical support logs were also included. For evaluating usefulness, we distinguish between existing support from the participants own devices prior to study start and that which is introduced in the case studies. For health efficacy, the impact of using the technology on aspects of quality of life such as function, independence, behaviour, mood or social engagement are evaluated.

5.2.3 Results

Six participants completed the study, including two women and four men between the ages of 65 and 78 years. A further three that enrolled dropped out due to illness or feeling daunted at the prospect of using the devices. A summary of participants' demographic information and assessment scores is provided in Table 8. Cognitive assessment scores were collected from the clinic through which participants were recruited. While certain scores are within the normal range for cognitive function, behavioural and executive symptoms in early stages of dementia are not always captured by MMSE and ACE. All participants were diagnosed with mild-moderate cognitive impairment based on specialised evaluation at the clinic.

Table 8. Summary of participant demographic information and assessment scores. Repeated tests show pre (1) above post (2) measurements.

			Participant					
			1	**2**	**3**	**4**	**5**	**6**
Background	Age		78	70	65	68	70	67
	Years retired		16	2	3	2	10	2
	Gender		M	M	F	M	F	M
Cognitive impairment	MMSE		27	27	24	26	27	23
	ACE		75	75	71	77	88	81
Quality of life	QOL-AD	*1*	33	44	41	51	45	50
		2	38	42	46	49	49	48
Function	FAQ–IADL	*1*	4	5	10	0	5	10
		2	6	9	5	0	5	12
Caregiver burden	ZBI	*1*	11	26	0	-	-	20
		2	1	28	0	18	3	13
Mobility	*LSA	*1*	76	84	50	66	100	66
		2	74	84	84	90	84	74
Activity	*GPAQ	*1*	27.5	10	20	39.5	70.25	7
	(hrs/week)	*2*	37.5	14	34.75	32.75	37	14.5

**Adapted: LSA score calculated assuming independent travel; GPAQ results show total active time for work (including household), leisure and transport (walking or cycling).*

Introduction to participants

Participant 1 (male, 78 years) lives with his wife and son. He has been retired for 16 years (at the time of participation), but follows an active weekly schedule involving diverse sports, hobbies and interests (e.g. badminton, pilates, art classes), that he often travels to by bicycle. This was the only participant who used his own smartphone for the study (other participants who already used smartphones owned iPhones, which were incompatible with the custom apps for data collection). His phone was paired with the smartwatch, and the two custom apps were installed for data collection and mobile self-reports.

Participant 2 (male, 70 years) lives with his wife, whom he depends on heavily for support in everyday life. She manages his schedule and they agree she is “his most important aid”. He struggles with fatigue and low energy (some days sleeping most of the day) but enjoys going out for walks when able. He owns an iPhone, and though he could not get used to the study phone, was able to operate the devices adequately for completing the study.

Participant 3 (65 years, female) lives with her husband. She is lively with a positive outlook and was highly enthusiastic about participating in the study. She has battled with psychosocial consequences of symptoms such as anxiety and feeling unsafe leaving the house (due to fear of not finding her way home). She keeps physically active doing housework, going out for walks and doing physical training at home. She has used an iPhone, but successfully learned to use the study phone to the same extent.

Participant 4 (male, 68 years) lives with his cohabiting partner. He describes the greatest impact his diagnosis has had as being the loss of his driver's license (which he had regained for two years just prior to participation). He keeps active taking his dogs out, visiting a local centre aimed at retired members of the community, and riding his bicycle. He also enjoys hobbies such as gardening and playing music. While he owns an iPhone that he uses extensively, he describes a disinterest in technology generally. He did not use the study phone for anything further than pairing it to the watch and answering mobile self-reports, since he did not feel comfortable learning to use a new device.

Participant 5 (female, 70 years) lives with her husband and has been retired for 10 years. She is highly active, with a physical training schedule including sessions five days per week. She is not experienced with smart technology, and though they own a household iPhone, she prefers to use a basic Nokia. She therefore did not use the study phone for other functions besides answering the mobile self-reports. She found the watch uncomfortable and did not use it for the study. A drop in motivation during the study is reported and attributed to psychosomatic symptoms (pain and fatigue).

Participant 6 (male, 67 years) lives with his wife. He retired earlier than planned due to health complications, and tries to keeps active and engaged by doing light housework, shopping, or going for walks. He has no prior experience with a smartphone. He has a basic Nokia that he can use for calls and reading – but not writing – text messages. Despite his limited experience, he did not feel it was too difficult to use the devices for the basic purposes required, e.g. turning it on/off, reading his step count, but needed help from his wife answering mobile self-reports.

Analysis 1: Data availability and utility

Here we examine whether adequate data was generated for the intended purpose of monitoring behaviour among the population of interest. Table 9 shows the duration in days for each case along with how many days data was recorded at all (Data), from the smartwatch, and from mobile self-reports. For mobile self-reports, a value of 0.5 is assigned for each of the two questions per day.

Table 9. Data availability

Participant	Days	Data		Watch		Self-reports	
1	98	98	100%	57	58%	39.0	40%
2	82	81	99%	4	5%	59.5	73%
3	60	60	100%	10	17%	53.5	89%
4	72	72	100%	8	11%	39.0	54%
5	87	86	99%	0	0%	49.5	57%
6	57	54	95%	2	4%	46.0	81%

While data was recorded nearly all days, only a small proportion of this was generated by the watch. One participant (5) did not wear the watch. Several participants had difficulty maintaining the connection between watch and phone, including noticing when they are disconnected. A further known cause was a technical fault whereby watch data is not transferred to the phone. This necessitated visiting the participant to perform a manual upload and reset both devices, which could take days or weeks to resolve, depending on participants' availability. Missing self-reports are mostly attributed to technical failures and usability issues rather than adherence. Participant 1 only started receiving the questions seven weeks into the study, and consequently agreed to extend his participation. Participant 6 could not answer self-reports without assistance from his caregiver. The cause for all missing self-reports is difficult to determine, since participants reported not receive prompts even when all others (including the research team members testing the setup) received all scheduled prompts under the identical configuration. Limited availability of watch data and self-reports does not necessarily inhibit the potential for behavioural monitoring in practice: all data types are recorded from the phone sensors (from which data was available throughout the study), and self-reports are for research purposes only. One noteworthy limitation is regarding step count, which is far more reliable from the wearable watch than from the phone which needs to be carried [17].

Visual inspection of the generated data indicates that this could indeed be adequate for behavioural monitoring. Figure 21 shows location data generated throughout the study for participants 4 and 5, indicating distance from home as a colour scale. These demonstrate that the devices were carried with them and show the potential for resulting data to reveal patterns in behaviour. For example, a daily rhythm is evident for participant 5 (movement from 6-8am near home, further around noon, and less consistent activity in the late afternoon), which contrasts with the less structured movement for participant 4. Figure 22 shows activity data for participant 2, again showing that the phone was used enough to generate activity bouts throughout the study. This figure reveals the habit of walking during the evenings that the participant reports having started during the study out of motivation to increase his daily step count.

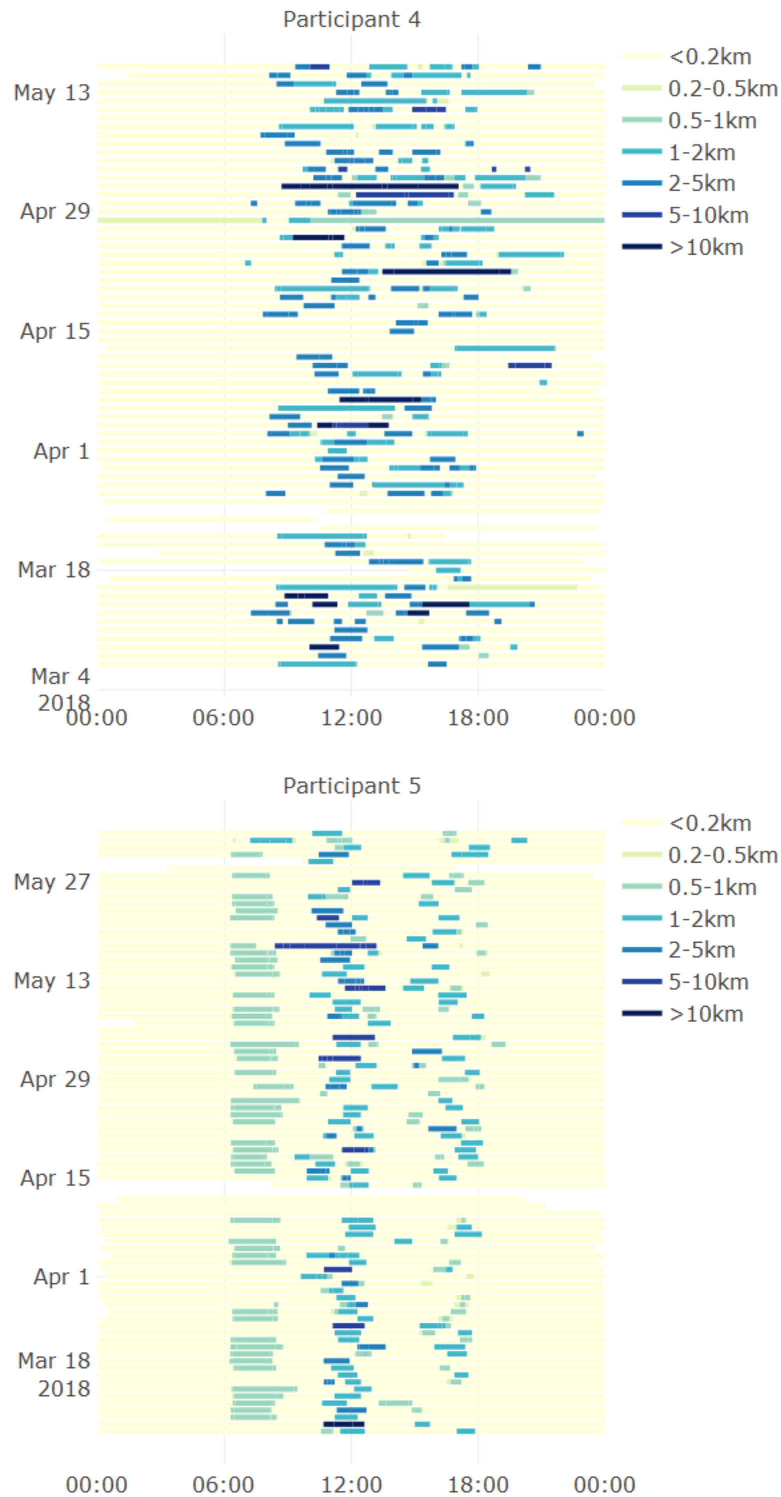

Figure 21. Location data for two participants throughout the study period. Time of day is shown along the horizontal axis and increasing date along the vertical axis.

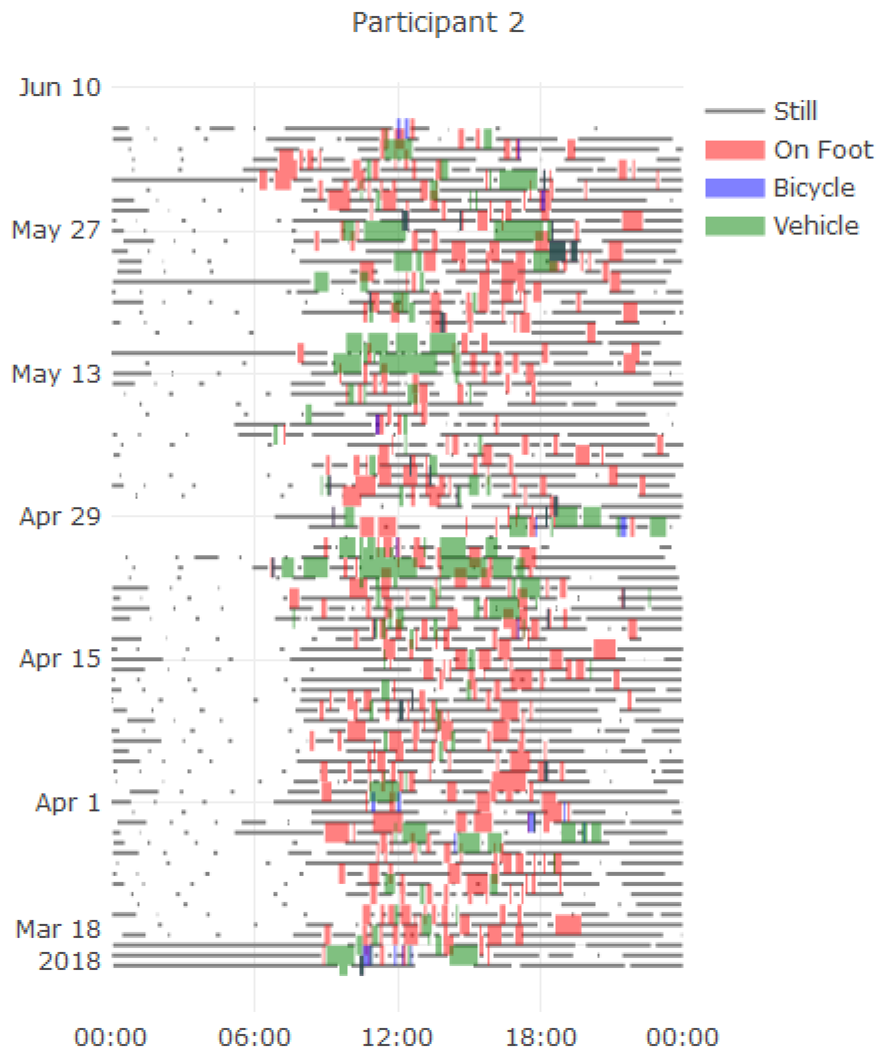

Figure 22. Activity data for participant 2 throughout the study period. Time of day is shown along the horizontal axis and increasing date along the vertical axis.

The three examples above are representative of all cases in terms of availability of useful data (i.e. for which the device appears to have been carried by the participant). This was sufficient despite variation in levels of interaction with the devices. Figure 23 shows screen-on time as an indication of device interaction for participant 3 who used the phone, participant 4 who did not, and participant 6 who appears to have attempted to use the phone at the start, with interaction diminishing over time. For all three examples, sufficient data was generated for extracting and analysing behavioural measures.

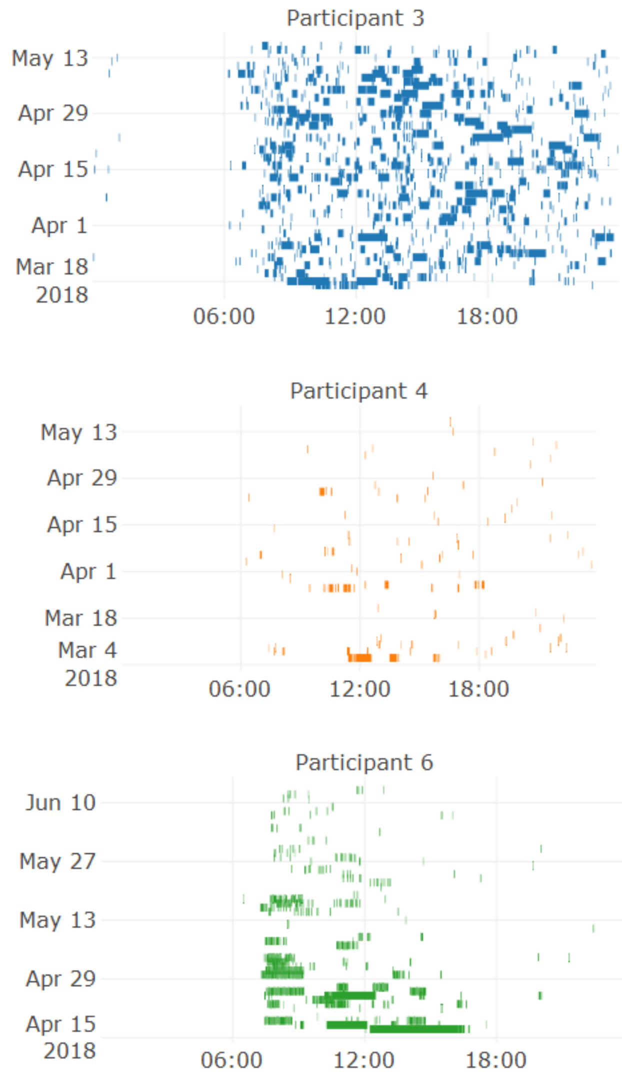

Figure 23. Screen-on time for three participants over their entire participation period

Analysis 2: Self-reported vs sensor-based measurement of behaviour

Daily activity and mobility

Self-reported daily levels of mobility and activity were visually compared with sensor-derived measures. Measures were selected for analysis from the complete set based on several factors. Four participants travelled out of town during participation, which affects measures such as *action range* or *time out of home* for all days away. For mobility, the measures MCP, time spent moving, and number of places visited were therefore included, which are only elevated on the actual days of travel. For activity, the measures active time, active bouts and steps are included. Steps are taken from the phone only due to the limited watch data and potential for large differences in the count from different sources to skew results if combined. A combined measure for mobility and activity is calculated as the average of the three measures for each.

By definition, most days are expected to be reported *normal* and show sensor measurements near the median, inevitably resulting in agreement between the signals. We therefore focus on deviations from normal to determine whether the sensor-based measures follow subjectively reported fluctuation in behaviour. Where they do not, we propose sources of such disagreement and infer potential advantages or disadvantages of each modality. Four illustrative results are included.

Figure 24 shows the sensor-based measures closely align with frequent (day-to-day) fluctuations in perceived activity levels for participant 3, whereas a slower trend (increase over first month) in the sensor-based measures for participant 5 is not reflected in their self-reported measures (Figure 25). This could indicate that changes that are more gradual are not as easily perceived by the individual. The mobility measures for participant 1 (Figure 26) again show alignment in the direction of fluctuations, only this time with some distinct deviations, most notably mid-April. This participant felt unsure about how to describe his mobility in relation to his schedule, noting that "normal for a Tuesday" is different from "normal for a Friday". This could explain why higher mobility might be reported as normal, requiring careful consideration of seasonality for detecting deviations in behavioural signals. A further phenomenon is depicted in the mobility comparison for participant 3 (Figure 27), for which subjective reports lie predominantly in the upper range (above normal), and are thus consistently higher than the sensor-based. This participant describes substantial impact the smartphone-based support had on her mobility, and shows an increase in both mobility and activity assessment results from pre- to post-study. It is therefore possible that these are reasonable perceptions given a longer period. Alternatively, the positive impact on her mood and confidence could have exaggerated her perception of her own mobility. Other possible sources of disagreement, particularly for isolated deviations, are mistakes using the mobile self-reports and forgetting to carry the phone. A final observation from the results is that the combined measures appear to agree better with participants' perceptions than each on their own. These are also potentially more robust against algorithm errors (e.g. misclassification of activities or travel trajectories).

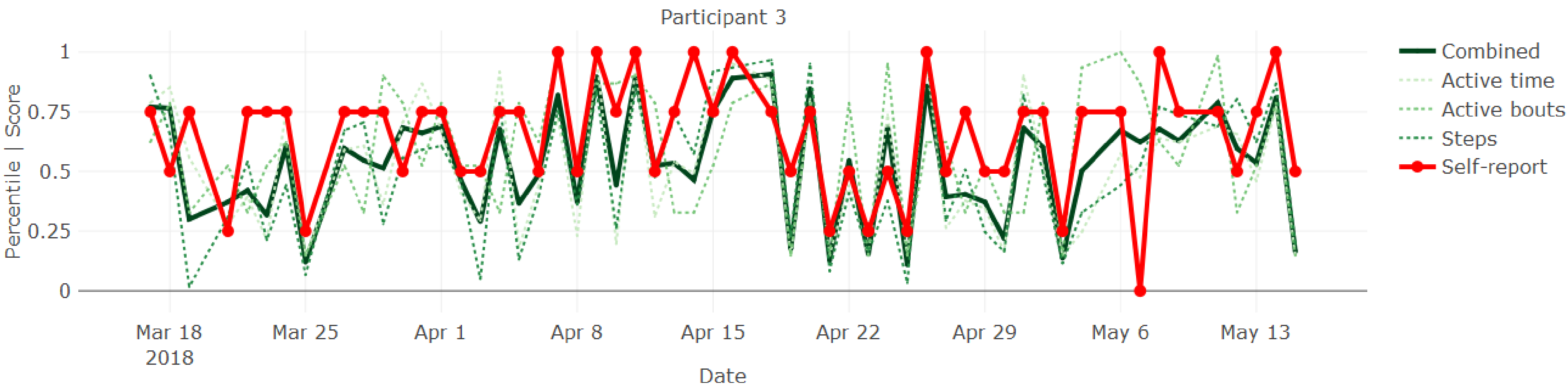

Figure 24. Activity measures and self-reports for participant 3

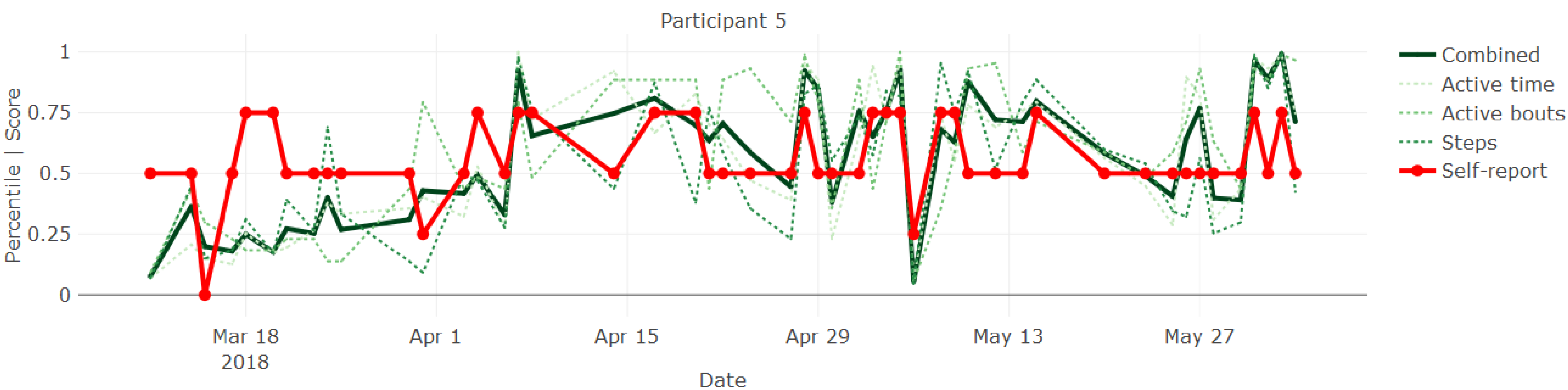

Figure 25. Activity measures and self-reports for participant 5

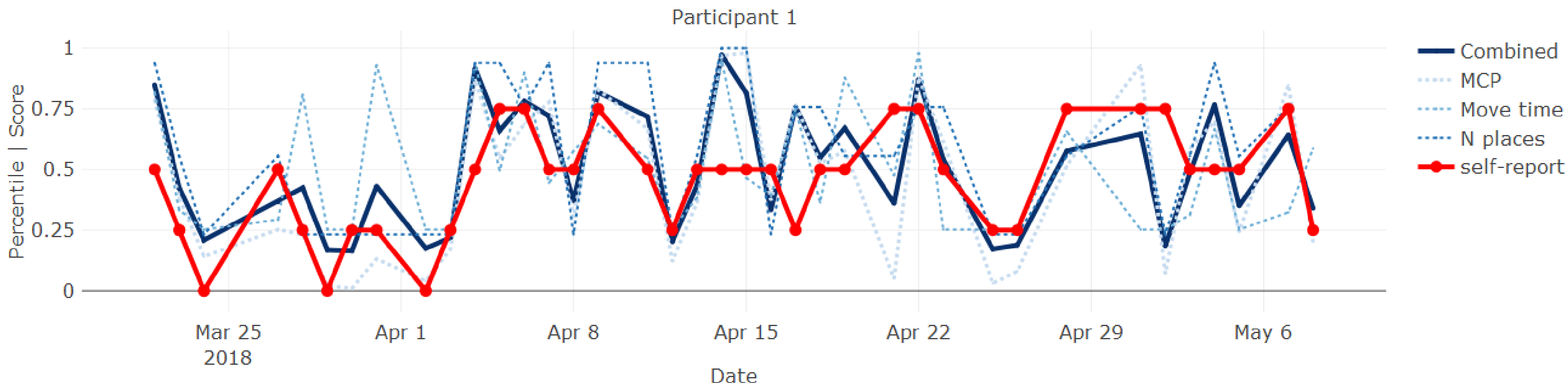

Figure 26. Mobility measures and self-reports for participant 1

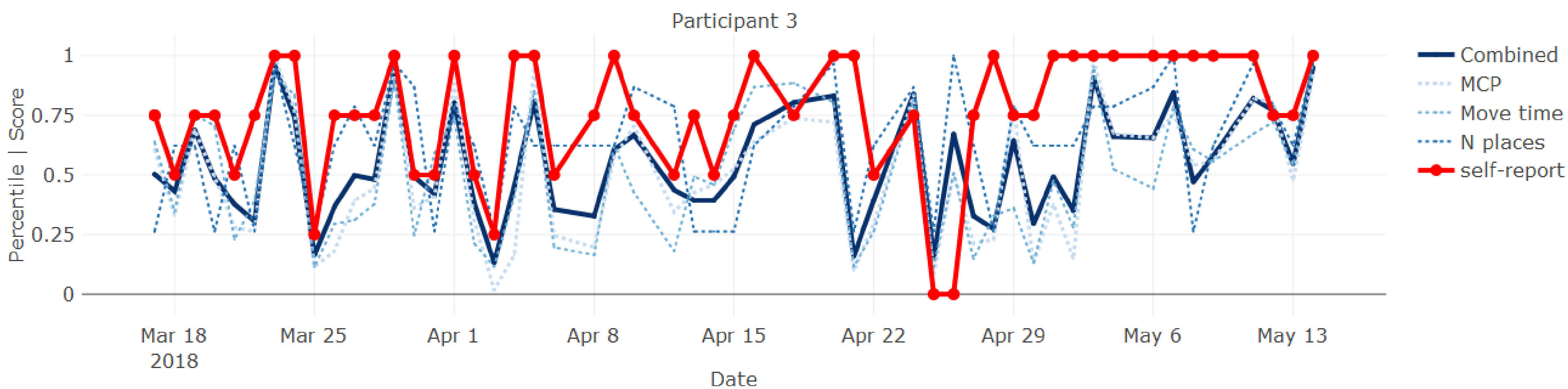

Figure 27. Mobility measures and self-reports for participant 3

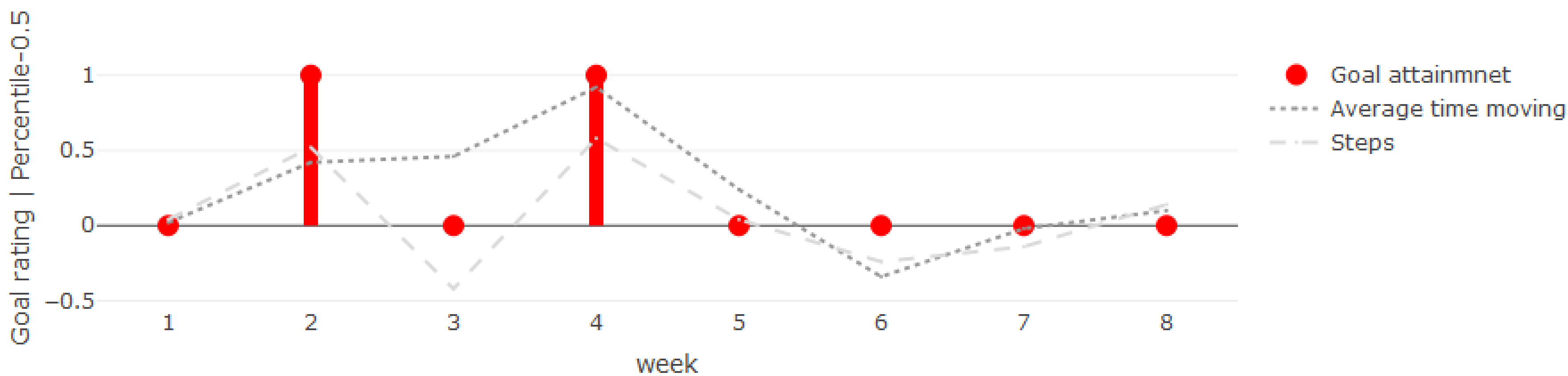

Figure 28. Weekly goal attainment (red) and relevant average weekly measures (shifted percentiles) for participant 6

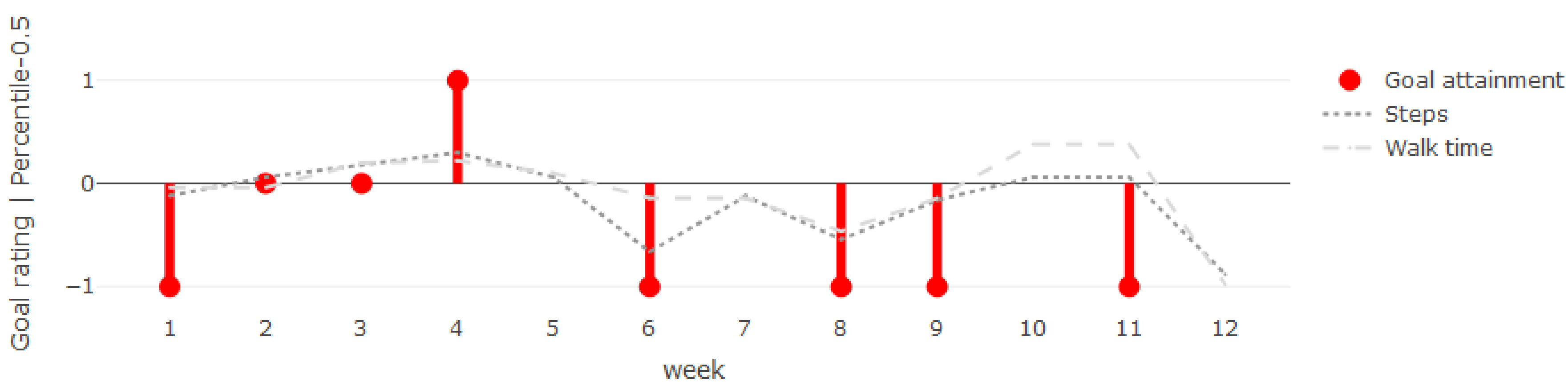

Figure 29. Weekly goal attainment (red) and relevant average weekly measures (shifted percentiles) for participant 2

Weekly goal attainment:

The goals defined by each participant at the start of their participation included getting out the house each day (participants 3 and 6), to walk longer daily (participant 2), to drive less and ride a bicycle more (participant 4) and to maintain an existing activity schedule (participants 1 and 5). Participants generally found it difficult to define goals related to their quality of life and required substantial guidance from the research team member facilitating goal definition. Furthermore, participants struggled to recall their goal over the duration of the study, often becoming distracted by the step count information once this was introduced. For example, when evaluating their goal attainment they might include information about how many steps they took or how far they walked despite their goal being unrelated. Both participants whose goals were to maintain a schedule did so because they were satisfied with their status quo, and since this is relevant for people with dementia due a risk of decline in functional capacity. Participant 1 in particular struggled to conceptualise a goal being to maintain (rather than improve upon) a status, requesting clarification each week when rating his goal attainment.

Participants' goals can be grouped into three categories:

- Target frequency of getting out of the home
- Increase/decrease in an activity type
- Adhere to an activity schedule

Here we use examples from each category to examine whether sensor-based measures could be used to evaluate goal attainment, comparing these with participants' perceptions.

Target frequency of getting out of the home:

Participants 3 and 6 followed the goal of getting out of their homes every day. This can be measured directly from the location data as the number of days per week that the participant went out at least once. Both participants went out 6-7 days per week most of the study, and rated their goal as achieved or over achieved (0 or 1) on those weeks. Participant 3 reported one week of under-achieving the goal (score of -1), which was also the only week she went out only 5 days (minimum for her participation period). Participant 6 twice reported over-achievement. While these weeks did not show any distinct difference in terms of the days per week he got out, they do show higher than usual step counts and time spent out moving between stays. This is demonstrated in Figure

28, which shows the average for these behavioural measures over each week along with goal attainment ratings.

Increase/decrease in an activity type:

Two participants defined goals of increasing an activity type. Participant 2 to walk more and participant 4 to cycle more (and drive less). This can be calculated from the extracted activity bouts as the amount of time spent in the relevant activity. For walking, step count is also included. Figure 29 shows the weekly goal attainment scores for participant 2 along with weekly averages for daily total steps and time spent on foot. The figure shows that the sensor-based measures fall under the median on those weeks where the participant perceives under-achievement, over the median for over-achievement, and close to the median for achievement. This indicates that the participant's perception of *increased walking* was in fact normal walking levels for the period of the study; and that there is agreement between the sensor-based measures and participant's perceptions should goal achievement correspond to normal behaviour.

A similar approach was used to measure bicycle and vehicle activity for participant 4. However, when rating his goal attainment, he usually explained that he had not been riding his bike and discussed other activities instead. Around halfway through his participation he first reported having started to ride his bicycle. This transition is evident in Table 10, which shows a marked increase in the total time spent cycling per week from the point at which he first reported cycling (week 5). The cycling time prior to week 5 is quite possibly the result of misclassifications in the activity recognition from Google, since confusion between vehicle and bicycle activities is a known issue [17].

Table 10. Weekly goal attainment for participant 4. Missing information indicated with "X".

Week	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Reported goal attainment	-1	-1	0	X	-1	0	0	0
Total time cycling (minutes)	23	0	26	12	78	65	50	40

Adherence to an activity schedule

Activity schedule goals are detected using information provided by the relevant participants about their schedule and locations. Participant 5 trains five days per week at a training centre for which the location was provided. Visits to the centre were detected based on distances between its location and the centroids of all *stay* events in the dataset. A summary of the number of days per week that she visited the training centre and her reported goal attainment scores is provided in Table 11, which shows little agreement between her perceptions and sensor-based measures. The notes from weekly calls offer some explanation for the disconnect: her answers tend to be substantiated by how active she was generally rather than her training schedule, with reference to long walks or step counts. Furthermore, she twice rated her goal as achieved with an explanation that the training centre was closed due to holidays, suggesting that since this was beyond her control and she remained active never the less, it was not perceived as under-achievement on her part.

Table 11. Weekly goal attainment for participant 5. Goal rating of 0 is "achieved", -1 is "underachieved" and 1 is "overachieved".

Week	**1**	**2**	**6**	**7**	**8**	**9**	**10**	**11**
Goal rating	0	1	0	0	-1	1	0	0
Training days	5	5	4	5	4	4	5	2

Overall, while in most cases a single sensor-based measurement of the goal did not correspond to participants' ratings, several related measures could sufficiently describe behaviour motivating these. This motivates a multimodal approach to sensor-based assessment/monitoring. In the next analysis we shift focus from monitoring to support from the devices for people with dementia.

Analysis 3. Qualitative analysis of user acceptance - usefulness and health efficacy

Here we present results from the qualitative analysis of interview data to evaluate how useful support from the devices was and the impact this support had on quality of life.

Pre-existing support from smartphones was taken into consideration and mostly continued alongside the personalised support offered in the studies. Participants 1, 2, 3 and 4 used smartphones prior to the study. All four participants describe using their smartphones daily or carrying it on them. Caregivers of participants 1 and 4 remarked on the dependence their spouse has on their phone, explaining that it is their "lifeblood" (participant 4) and how they might interrupt a meal to capture information on their phone before forgetting it (participant 1). Examples of purposes given for which the phones are used include calendar/reminders, taking and reviewing pictures, social, leisure, news and weather information applications, and to make payments.

Table 12. Personalised support offered to participants based on individual needs. Responses shown with + or – to indicate positive or negative perceptions of benefit from the support, stronger responses indicated with ++ or --.

App/feature	Description	P	Benefit/purpose	
Vibration alerts on the watch	Notify user when the phone rings or receives notifications	1	+	Function
		2,3	+	Function, social
Contact pictures in the phonebook	Remembering faces/names, and to feel safe when phone rings	1	+	Memory
		2	+	Memory, safety
Google Fit	Tracking activities or activity levels, e.g. step count	2,3,4,6	+	Motivation/health
		1	- -	
Find Home	Navigation support to find home, including a shortcut on the home screen	3	++	Function, safety
Location tracker (“My Family”)	Tracking and reviewing routes, and for a caregiver to track the user’s location	3	++	Memory, leisure
		5	+	Safety

Results from the analysis of post-study interviews regarding usefulness of the personalised support offered to participants are summarised in Table 12. Interview recordings were analysed to extract how the participants benefitted from the support and to what extent. The same application might fulfil different purposes for different participants, as is the case for the location tracker provided to participants 3 and 5. Participant 5 describes enjoying reviewing her routes after a journey for fun (leisure) and her caregiver adds that she often forgets where she has been, resulting in her carrying a pen and paper to record names of places she visits (memory). The same app is used for participant 3’s caregiver to locate her, fulfilling a need for safety. Another example is the picture-dialling feature whereby participants add pictures to contact details in their phonebooks. While this offered memory support to participant 1, participant 2 reports feeling safer when the phone rings if a picture is shown. Responses to the smartwatch varied substantially. Two participants did not like it at all, participant 5 explained that *“it's big and it's heavy, and I must take care of it and have to take it everywhere with me”*, and participant 6 found the rubber strap to be uncomfortable especially in warm weather. Other participants found enjoyable or convenient, participant 4 adding that he did not notice it at all and preferred it to checking the time on his phone.

Overall, the support was perceived as beneficial. Two cases stand out as being particularly negative or positive. Participant 1 was provided with Google Fit based on an interest in information about his activity. He misunderstood that he should manually enter all of his activities into Google Fit as a means of data collection in the study. This caused considerable effort on his part, and led to anxiety over mistakes in recording the activities. Explaining the misunderstanding to both the participant and caregiver dissuaded him from using the app for data capture, however confusion over the apps purpose and our data collection methods persisted throughout. Participant 3's experience was overwhelmingly positive. She describes her participation in the study as having *"given her a new life"*, primarily attributed to personalised support selected to help her navigate home and for her caregiver (husband) to track her location. She explains that *"I have a new life… my husband is completely calm… Can you imagine, I can go anywhere! … [with the "find home" feature] I have peace of mind and inner calm"*. Her caregiver describes no longer being scared of her getting lost, and notes the impact on her: *"We [him and their children] can indeed notice a huge difference, really. She is completely changed. She has become super positive, and has her good humour back"*.

Participants had varying views on the impact the technology and broader intervention had on their everyday functioning, health and wellbeing. Participants 1 and 5 perceived no benefits, both stating that they were active to begin with and were satisfied with their existing coping strategies. Participants 2, 4 and 6 all reported that they found tracking their step count to be motivating, of whom participants 2 and 6 believed they had increased their activity as a result (for both their pre/post activity assessments also show an increase). Participant 3 perceived considerable impact on both functioning in everyday life and health status, reporting reduced anxiety, improved mood, increased activity levels, and having implemented more effective schedule management using the study devices.

To assess overall acceptance, participants were asked whether they would be interested in using the support beyond the study. Only participant 5, who had no previous experience with smartphones, expressed no interest at all, explaining that the benefits were not worth the effort and she felt satisfied with her pre-existing coping strategies. For participants who used smartphones prior to the study, interest was mostly dependent on being able to implement the setup with their own devices, with the exception of participant 3 who wished to continue with the study setup. All participants, including those without personal interest in using the technology, felt that it could benefit other people with dementia.

5.2.4 Discussion

Principal findings

This work describes six in-depth case studies used to evaluate the feasibility of using mobile and wearable technology (smartphones and smartwatches) to support rehabilitation among people with dementia. Results demonstrate the potential for data from personal devices used in a real-life context among the target population to reveal behavioural patterns, and that this is irrespective of the level of device use beyond basic operation. A comparison of participants' self-reported daily activity and mobility levels with objective, sensor-based measures indicates that sensor-based measurement reflects participants' perceived fluctuations in behaviour, and may reveal gradual trends not detected by participants themselves. Sensor-based measurement could be used to track related goals by offering rich, multimodal information related to function and engagement. This may be beneficial for collaboratively following goals, since several patients had difficulty recalling their goals over time or describing goal attainment. Qualitative analysis of user acceptance indicated that personalised support offered by smart technology addressed functional, memory, safety, leisure and psychosocial needs, where many of these depend on familiarity of the device/platform for user acceptance. Four participants perceived this support to positively impact their health, mostly regarding motivation to be active, with one participant further describing considerable positive impact on perceived anxiety, independence, activity and caregiver burden.

Future work

This feasibility study has identified a number of key areas for further research and development. Regarding technical developments, compatibility with other platforms and devices is imperative for user acceptance and adoption, especially as people with dementia increasingly use smartphones and wearables prior to disease onset. Three participants who already used iPhones without difficulty prior to the study found the study phones (Android platform) too difficult to learn to operate properly. Further development is also recommended to improve the reliability of obtaining data from a connected wearable, since poor availability of smartwatch data was a technical limitation of this study. While smartphones alone are sufficient for mobility assessment (if carried), wearable devices are likely to provide more accurate descriptions of activity (e.g. step counts), especially for periods spent at home, thereby complementing out-of-home mobility measurement. From a clinical perspective, an interesting technical development is to share information obtained through behavioural monitoring with participants, i.e. people with dementia and their caregivers. While this was not implemented in this work, information about step count from installed applications was of interest to all participants and motivated increased activity among four. Considering difficulties many participants had defining goals, this should be addressed in more detail in future research on incorporating sensor-based monitoring.

The results of this feasibility study suggest that personalised smartphone-based support positively impact quality of life among people with dementia. This warrants further investigation on a larger scale to quantity and confirm such impact. We have demonstrated the potential for sensor-based mobility and activity monitoring to reveal patterns in behaviour. This further motivates larger scale and longer-term studies to gather the data necessary to develop algorithms for detecting and predicting changes in condition status.

Implications for clinical practice

Results of this study indicate that smartphones and wearables offer pervasive support that could benefit people with dementia, and that through this role, also generate rich data that can be used to monitor behaviour for assessing function and engagement. Personal devices could therefore fulfil two important roles in rehabilitation – support and assessment. This has far-reaching implications for innovation in non-pharmacological approaches to dementia care. The use of familiar, available devices supports user acceptance and transferability of solutions, and due to their adaptability, without sacrificing personalisation. Availability of objective behavioural measures that can be shared within the care network supports participatory care, and gathering this data continuously supports the development of predictive and preventative care approaches.

Conclusion

This work provides some of the first evidence describing the dual role of personal devices in rehabilitation for dementia by offering both personalised support in everyday life and monitoring activity and mobility behaviour. Results show promise for smartphones and wearables to drive personalised, participatory, predictive and preventative approaches to dementia care. Core contributions include: results demonstrating that data gathered under real-life conditions is adequate for revealing behavioural patterns, initial evidence showing potential advantages of sensor-based measurement over self-reported behaviour e.g. for detecting gradual trends or providing multi-faceted insights into goal attainment, and qualitative reports from participants describing usefulness of the support and its impact on their health and wellbeing.

Abbreviations:

ACE: Addenbrooke's Cognitive Examination

API: Application programming interface

CDF: Cumulative distribution function

FAQ-IADL: Functional assessment questionnaire – instrumental activities of daily living

GPAQ: Global physical activity questionnaire

GPS: Global positioning system

LSA: Life-space assessment

MCP: Minimum convex polygon

MMSE: Mini mental state examination

P4: Predictive, preventive, personalised and participatory

QOL-AD: Quality of life in Alzheimer's disease

ZBI: Zarit Burden Interview

References

Article references are merged with thesis references for document continuity. Reference numbering in this section is therefore adapted from the original submitted manuscript [20].

Chapter 5 conclusions

This chapter has documented a feasibility study aimed at fulfilling the third objective of this PhD research: To evaluate feasibility *of the technology-supported rehabilitation concept in terms of supporting patient quality of life and informing care.*

Findings from a workshop held with healthcare professionals described at the start of this chapter suggest that information about patient mobility and activity is useful, and should show trends and include multiple measures to be informative, thereby supporting the clinical relevance of the results obtained in the case studies.

Through a series of six case studies this thesis has shown how selecting existing, widely available tools according to individual needs benefitted people with dementia in everyday life by supporting memory function, navigation, communication and safety needs.

This thesis has further shown how data collected from smartphones and smartwatches can be used to calculate a range of mobility and activity measures, and that these could be highly useful in revealing gradual trends or informing discussion on goal attainment by providing multimodal information about related behaviours.

Next, the final chapter reflects on these findings in relation to the research questions introduced in section 1.2, and on implications and impact of this research for patients and caregivers, clinical practice and healthcare systems design.

Chapter 6

DISCUSSION

This chapter answers and reflects on research questions introduced in Chapter 1, highlights contributions made in the research process, their implications and also includes future directions proposed to build upon the contributions. The thesis concludes with final reflections on what has been learned in the process of carrying out this research.

6.1 A more detailed picture of the envisioned dementia care

The dementia care system in focus within this PhD project is introduced in Chapter 1 showing the patient and caregiver supported by technology that provides monitoring capabilities to inform a collaborative care strategy between care providers and recipients (see Figure 3). Through identifying opportunities (explore), development of a technological solution (create) and its implementation in practice in a real-life context (evaluate), this thesis has provided further detail to describe the role of technology in this system, as depicted in Figure 30.

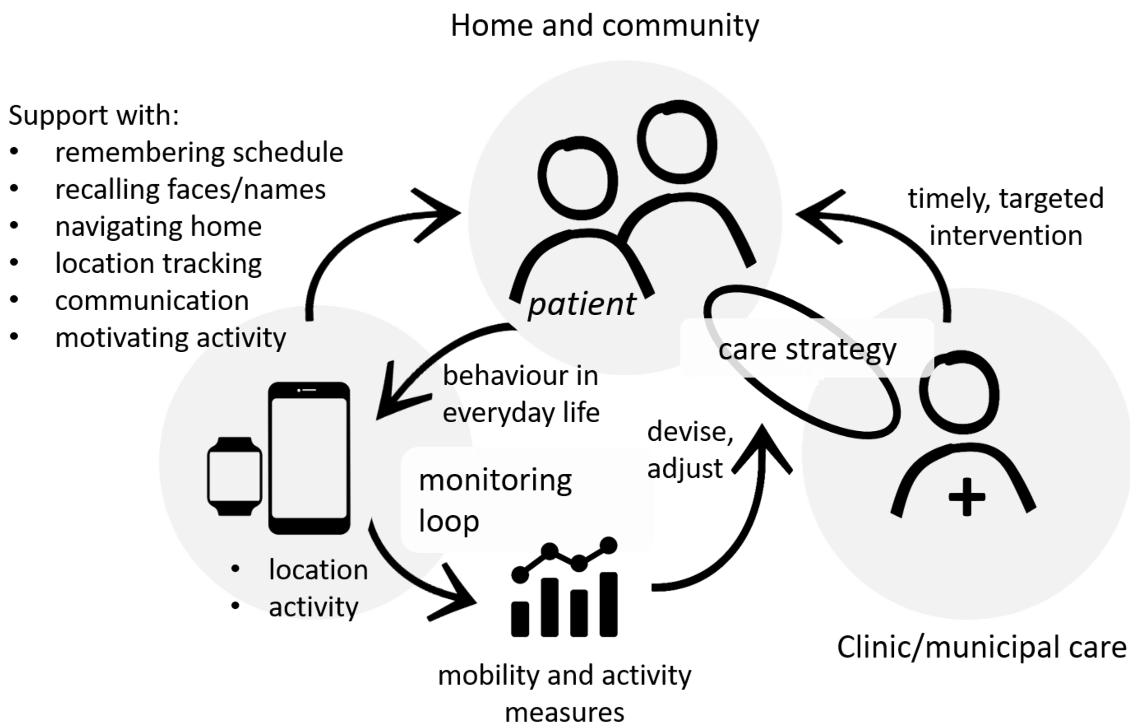

Figure 30. Outcomes from the thesis projected onto the system view introduced in Chapter 2

6.2 Answering the research questions

This section reflects on the four research questions defined in section 1.2 and discusses how these have been answered through this thesis. Together, these answer the overarching question of how healthcare systems can incorporate mobile/wearable technology to fulfil both support and monitoring roles to improve patient quality of life and to inform care.

6.2.1 *Which needs of the dementia care network might be supported by mobile/wearable technology, and how?* (Research questions 1 & 2)

The first two research questions concern meeting needs of the dementia care network with smart, mobile and wearable (pervasive) technology. Let us first consider the dementia care network in terms of people with dementia, their family caregivers, and healthcare professionals. This thesis has focused on the needs of people with dementia for support in everyday life. Regarding the needs of their caregivers, these are partially met as a consequence of meeting people with dementia's needs regarding e.g. safety and independence by relieving the burden on caregivers. The needs of healthcare professionals are specifically addressed through the provision of clinically relevant information, which is discussed further in answering research question 3 (see section 6.2.2).

These first two research questions are answered through several parts of the thesis. In Chapter 3, a set of needs is identified in section 3.1 which are extended and related to capabilities of pervasive technology in section 3.2. This exercise indicated that needs that might be fulfilled by pervasive technology include: functional support with activities of daily living and memory, psychosocial needs related to orientation, social engagement and mood, and the need for safety. Technology for addressing these needs includes smartphones in combination with applications for calendar management, communication, maps/navigation, clock, social, and leisure/entertainment (Table 4 in Chapter 3). The first impression produced in Chapter 3 regarding which needs could be fulfilled by pervasive technology and how is largely speculative. This is based purely on functionality without knowledge of whether they do in practice in a real-life context. A clearer answer is developed through testing with users in early pilot studies (section 4.1, published in [1]) and in-depth case studies (section 5.2, published in [20]). Initial pilot testing suggested that calendars/reminders were best suited to people with dementias needs (in terms of both usability and usefulness), and navigation support least. However, in the feasibility evaluation, one participant in particular who was specifically interested support getting around independently navigation support to be highly beneficial. This indicates, as expected, the dependency of usefulness on personalisation to individual needs. The feasibility evaluation further indicated that support from e.g. smartwatch-based notifications, picture contacts and step-count tracking are useful for facilitating communication, perceived safety, and motivating activity.

Two non-functional needs identified during both the field study (section 3.1) and user-testing (section 4.1, published in [1]) include personalisation and familiarity. Personal mobile/wearable technology is highly promising in meeting these. Four of six case study participants were already familiar with smartphones as a resource for support in everyday life, which is likely to be ever more common in coming years. Personalisation was achieved in the case studies (section 5.2, published in [20]) by matching functionality to participants' expressed needs, through which each participant's study setup was unique to their pre-existing strategies and additional interests.

The capability of mobile/wearable technology to meet the needs of people with dementia is influenced by factors such as age as elderly populations are less accustomed to these technologies and condition symptoms regarding e.g. learning, memory and perception. It is therefore important to reflect on these factors based on experiences and findings from this research. Perhaps most noteworthy is the research participants' (people with early-stage dementia) feeling overwhelmed or daunted by the technology, which may be partly attributed to inexperience and/or cognitive impairment, and was a reason stated by at least three participants who dropped out of studies conducted in this research. Other participants who completed the case studies using the technology for at least eight weeks remarked that having been told at orientation that they could not break the devices or do anything wrong by pressing the wrong buttons had helped them to feel comfortable trying to use them. Operating a device such as a smartphone requires the user to perform a predefined sequence of tasks, such as for answering mobile self-reports where users should swipe down the notification tray, select the prompt notification to open the questionnaire, select a response, and press "answer". This ability may be affected by cognitive impairment (a known example is the reduced ability to prepare food or a cup of tea which also requires a sequence of tasks to be performed), and could therefore be a factor that limited participants' ability to use the devices. Other difficulties encountered by research participants that may be attributed to age or dementia symptoms include getting lost when navigating through the device menus (e.g. due to affected perception or overview), difficulty swiping as a mode of interaction with the devices (e.g. due to this being unfamiliar or poor dexterity), and difficulty learning to use a new platform, i.e. where iPhone users could not learn to use the Android smartphones. While the influence of these symptom-related factor raises important concerns regarding the long term perspectives on usefulness, it is also apparent that future generations – for whom the use of smartphone-based tools may be more engrained – are less likely to be hindered by these factors to the same degree as todays.

In summary, these two research questions are together answered in this thesis through an exploration of opportunities in Chapter 3 that are developed in section 4.1 (published in [1]) and evaluated in section 5.2 (published in [20]). Together, these indicate that a range of everyday life needs by people with dementia could be met by pervasive technology that further satisfies familiarity and personalisation as two important criteria for user acceptance.

6.2.2 *How can data generated by mobile/wearable sensors inform dementia care approaches?* (Research question 3)

This thesis has focused on location, activities and step-count data to measure lifespace mobility and activity. To answer how these measures can inform care, let us first consider their relevance for the clinical condition in general terms. The introductory chapters (Chapter 1 and Chapter 2) refer to calls for an emphasis on function in everyday life and community engagement in care for the elderly and people with dementia [27], [52]. In the exploration phase of the project, location and activity data are identified as being potentially indicative of function and engagement by revealing the extent to which a person goes out and how active/sedentary they are. These are both related and complementary: going out of the home requires activity, yet one can remain home and be highly active or travel far from home without being particularly physically active. Clinical relevance of mobility and activity are further validated by related literature described in section 4.2 (published in [20]) linking mobility to social engagement, functional capacity, affective state and caregiver burden [134]–[137], and through a workshop with healthcare professionals at the dementia and memory clinic. The workshop (section 5.1) confirmed that information about both activity and mobility would be informative for providing care, but raised important limitations, particularly regarding the need for further qualitative data to explain behavioural changes.

Building on the premise that these are relevant measures for monitoring people with dementia, insights gained through monitoring mobility and activity using pervasive technology in a real-life context are now considered in more detail, including how these might be applied to care in practice. This is addressed through the feasibility study presented in section 5.2 (published in [20]) in which location and activity data was generated in a real-life context among people with dementia over at least eight weeks and used to calculate a set of mobility and activity metrics. These measures revealed behavioural patterns even where device use is minimal, showed a gradual trend not detected by the participant, and indicated that a combination of various activity and mobility measures may provide explanations for how participants perceive their goal attainment even where directly measuring the specific goal does not. From these findings, several ways in which mobility and activity monitoring might inform clinical practice are inferred. Detecting gradual trends enables timely intervention in case of decline, and provides a means of measuring outcomes once the intervention is introduced. Combining various activity and mobility measures could help pinpoint *how* the patient's behaviour is changing, e.g. are they walking less frequently or not as far, which can help guide further questions and investigation or the selection of engaging activities to suggest based on the nature of a change in lifestyle.

In summary, findings throughout the thesis suggest that data-derived insights regarding mobility and activity could provide relevant information to healthcare professionals about patients' function and engagement, both of which are key aspects of quality of life, and that this should augment rather than replace detailed information from patients and their caregivers. These behavioural measures could be used in rehabilitation to trigger interventions, guide their formulation, and measure their outcomes.

6.2.3 *How can pervasive technology, through fulfilling support and monitoring roles, improve quality of life among people with dementia?* (Research question 4)

Quality of life encompasses myriad factors weighted differently according to individual circumstances, needs and interests. Two key aspects of quality of life in relation to dementia are function in everyday life and social or community engagement, which are touched on in answering the research questions above. The support provided in everyday life is now linked to the monitoring role through the mutual purpose of improving quality of life.

At first glance, the support and monitoring arms of the case studies in section 5.2 appear disconnected. Tools such as calendars, navigation support or smartwatch-based vibration alerts, are provided and yet monitoring does include measurement of how many appointments they remembered, whether they found their way home, or if they answered a message or call – instead including measures of geographical areas/distances covered, periods spent active or out of the home, places visited and steps taken. What links the support provided to measures monitored is quality of life, specifically function and engagement. By helping an individual to remember their appointments, communicate and find their way independently, it is anticipated that they will attend more appointments, engage in more social activity and make more trips out of the home (e.g. to the grocery store or to walk the dog) independently, which is expected to manifest as increased activity and mobility. In this way, the support offered contributes to improved function in everyday life and social engagement, and mobility and activity measures offer a way to probe these outcomes. The connection is more apparent for some needs than others. Where a person does not leave the home for fear of getting lost, it quite obvious that support with finding their way should result in greater out-of-home mobility. On the other hand, support remembering faces and names does not obviously lead to more mobility/activity. However, even here a link is plausible. One participant from the case studies described having difficulty attending social functions with 10 or more people, since he could not keep track of who everyone was, and writing notes with pen and paper (his usual strategy) was futile on that scale. Supporting him with a means to quickly recall information about the attendees could therefore encourage him in attending larger social functions.

The *impact* of providing technology-based support in everyday life on mobility and activity is not measured in this thesis, since this would require a larger, controlled study. As an important precursor to such studies, this thesis has demonstrated the potential for support from pervasive technology to improve quality of life, and the potential for this to be measured through indicators (mobility and activity) using sensor data from these same devices. Consequently, necessary tools are provided for rehabilitation interventions aimed at improving quality of life among people with dementia. Such interventions might follow an iterative process of offering personalised support, measuring its effect, and adjusting the support based on information gathered through continuous measurement in an everyday life context.

The case studies (Section 5.2, published in [20]) further afforded a detailed look into each individual experience using the technology provided. One case story in particular exemplifies how functional support can influence mobility, and the domino effect of this can have on other aspects of quality of life. Participant 3 expressed an interest in help with getting out independently as she was afraid of getting lost, for which she was provided navigation support ("find home" button to initiate turn-by-turn navigation) and an application for her caregiver to track her location. Prior to the study, she had needed to arrange for a companion to join her to go out for walks and found this very limiting in terms of when and for how long she could go out. With the support tools, she reported being able to go out far more often and longer. The positive knock-on effects she describes are many. During multiple interactions with the research team, and particularly in the post-study interview, she repeatedly expressed feelings of her anxiety being lifted from her, of freedom, independence and inner calm. She and her caregiver both describe improved mood and improved relationships with family. They describe the impact this has had on her caregiver, who no longer worries about her when she goes out, and who feels relieved by her improved state of mind.

Stories like that of participant 3 demonstrate how support from pervasive technology can improve quality of life according to individual goals, and how this might be reflected in behaviour that can be measured from sensor data. This provides novel evidence to support further research and progress towards incorporating these technological tools and data elicited into clinical practice.

6.3 Core contributions and impact

The core contribution of this work is the application of mobile/wearable technology and the data this generates in dementia rehabilitation using an engineering systems perspective to improve patient quality of life and advance personalised, participatory, predictive and preventative (P4) healthcare. This stems from several novel contributions offered through answering the research questions and fulfilling each of three project objectives in chapters 3-5 (explore, create, evaluate), towards research and practice across domains of health system design, health technology and dementia rehabilitation – and beyond. These contributions and their implications are summarised in this section.

This thesis shows how widely available technology can provide personalised support in everyday life to people with dementia, meeting a variety of functional, psychosocial and care needs. This contributes towards clinical practice with a knowledgebase of potential support tools that are easily accessible to patients through their smartphones where these are already used. For example, such information could benefit dementia consultants seeking assistive tools to meet individual needs expressed by the patients they visit. Through investigating user acceptance of the mobile/wearable technology-based support, a further contribution is made towards both design and technology fields in the form of design knowledge (e.g. factors influencing usability or usefulness) to enhance adoption of these technologies among elderly or cognitively impaired users.

A core contribution of this PhD project is the novel behavioural monitoring solution developed to measure mobility and activity using sensor data from personal devices e.g. smartphones and connected wearables (section 4.2, published in [17]). This contributes to engineering design research and practice with reproducible and scalable tools for understanding human behaviour that could augment established design methods and inform system design. These analytical tools offer further contributions towards health and health technology fields. The behavioural monitoring solution offers a foundational setup for gathering mobility and activity measures that could be used directly or built upon to investigate, e.g. visualisation and feedback or data integration steps. Mobility and activity measurement is relevant for a range of other healthcare applications besides dementia, e.g. to promote active ageing, lifestyle-related chronic illness, rehabilitation following injury or surgery, or in mental health.

In this work, the behavioural monitoring solution is applied towards rehabilitation among people with early-stage dementia. Here, both the support and monitoring contributions described above are merged and implemented in a real-life setting among people with dementia. This has provided novel evidence describing the feasibility of mobile/wearable technology for dementia rehabilitation in terms of data utility, user acceptance, health efficacy and clinical relevance (section 5.2, published in [20]). This adds to the limited body of evidence on non-pharmacological interventions for dementia with case stories describing potential impact on patient quality of life to direct future studies.

Limitations or knowledge gaps were identified within healthcare system design, health technology and dementia care in Chapter 2. This thesis has addressed these by synthesising contributions from each domain for their mutual benefit and advancement. Within healthcare systems design and engineering design generally, the need for approaches geared towards integrating new data sources, large datasets and the insights these generate into healthcare systems is recognised. This work brings data-driven methods for understanding human behaviour to design research for the development of such approaches, e.g. through work published as part of this research on *sensing behaviour in healthcare design* targeting the engineering design research community [21]. Health technology development efforts, and particularly those targeting elderly populations, face user acceptance and adoption obstacles for which engineering design approaches and consideration for clinical implementation in practice may be advantageous. Here, this work contributes with a demonstrated engineering systems perspective, knowledge on acceptance of smartphones/smartwatches among elderly and cognitively impaired users, and evidence from implementation in a real-life context, e.g. in the article published as part of this work on user-centred design for a health technology audience (in *Healthcare Technology Letters*) [1]. In the clinical domain, non-pharmaceutical approaches to dementia care are resource heavy and may benefit from pervasive technologies such as personal mobile and wearable devices as a means of providing support to patients throughout everyday life, and by offering a remote and automatic means for gathering continuous, objective data for assessment of patient outcomes. This work provides a prototype mobile/wearable technology solution to augment goal-oriented rehabilitation by fulfilling this proposed dual support and monitoring purpose, and demonstrates its feasibility for implementation in practice [17], [20].

Chapters 1 and 2 introduce the vision for future healthcare systems as technology-supported, decentralised care encompassing the P4 framework of predictive, preventative, personalised and participatory healthcare. The contributions of this PhD project described above have many implications for realising this vision. Implications regarding the pervasiveness of mobile and wearable technology are decentralisation and access to care. The availability of popular personal devices is noted throughout this thesis, and allows care delivered through this medium to be accessed by many and permeate our everyday lives rather than being confined to a clinical setting. This provides insight into patients' health status between interactions with healthcare professionals, relieving the burden on both care providers and recipients regarding meeting and transferring information in a clinical setting. Implications of the technology-supported rehabilitation presented in this thesis for advancing P4 healthcare are as follows:

- *Predictive and preventative:* Sensor-based behavioural measures were able to reveal patterns in behaviour and show gradual trends not reported by participants themselves. This could support the detecting of decline (e.g. in mobility) to trigger intervention or preventative strategies against consequences such as depression or falls.
- *Personalised:* Research reported in this thesis shows how the use of flexible, modular pervasive technologies enabled the provision of personalised support by selecting from a range of existing applications. Furthermore, the behavioural insights showed distinct differences between participants, e.g. in how structured their routines were, transport habits or daily rhythms regarding sedentary/active times of the day. This could guide personalised interventions to fit lifestyle patterns. Personalisation in both the support and monitoring of patients further supports the practice of personalised goal setting and following as a component of rehabilitation interventions.
- *Participatory:* This thesis has developed a technological for generating information about behaviour that measures indicators of function in everyday life and social/community engagement. These could be shared amongst the care network to empower patients to

participate in devising goals and care strategies. All participants were interested in information about their step count and in feedback generally about their behaviour (e.g. reviewing their travel routes). Tracking step count motivated four participants to be active, and influenced how participants defined goals related to quality of life. This suggests that the behavioural measurement solution developed and implemented in this work could aid participation in rehabilitation practices among people with dementia.

This section has reflected on several contributions made in this work and their implications for engineering design, technology, healthcare, and ultimately the realisation of future healthcare systems within the P4 framework. This work has also deepened an understanding of limitations of pervasive, mobile/wearable technology – which cannot address every need nor provide all the information required for dementia care. Findings of this work support the notion that the use of support/monitoring from pervasive technology cannot and should not replace interaction between healthcare professionals and patients. Instead, it should enhance care provider-recipient interactions and reduce the time and effort these require by generating information and facilitating its transfer. Further limitations regarding e.g. data validity, usability or other challenges facing clinical implementation in practice are discussed in the following section to reflect on what contributions are still needed, highlighting important next steps for this research field.

6.4 Future work

This section proposes directions for future work in the form of clinical studies and technical development as well as regulatory and infrastructural considerations necessary to build upon the outcomes of this thesis. The proposed scenario in which patients use smartphones with connected wearables for support and monitoring is considerably different from clinical practice today. Healthcare professionals would require knowledge of available software tools and would need to understand how to interpret and act upon new types of behavioural data. Introducing sensor-based measures for assessment requires new data infrastructures that comply with regulations regarding, e.g. security, ethics and good clinical practice standards. Potential unintended consequences need to be identified and mitigated. Some of these tasks are greater than others. For example, knowledge of available tools will likely develop naturally over the years: today dementia consultants regularly discuss the use of paper-based calendars to support a structured everyday routine among the people with dementia and caregivers they work with, which could foreseeably transcend into discussion about using a calendar app on their smartphone for the same purpose. On the other hand, introducing new data infrastructures is a monumental task demanding significant planning and development efforts.

This PhD project has taken a step towards the proposed scenario and, in doing so, identified important next steps to take. This work has contributed towards the knowledgebase of available technological tools for support and begun to demystify the potential role of sensor-based behavioural measures in dementia care delivery. Working closely with patients, caregivers and healthcare professionals has helped to reveal great potential for pervasive technology to benefit care and shown that there are myriad finer details to be examined in order to reap these benefits. Two key steps are recommended to advance progress in this research topic: larger scale studies designed to measure the impact of the proposed technology-supported rehabilitation approach on quality of life; and further studies addressing clinical implementation in practice.

Section 6.2.3 describes how pervasive technology might improve quality of life among people with dementia based on findings from this research. The detailed insight afforded by in-depth case studies have paved the way for planning larger studies that build upon what was found to be useful or informative, or not, and why. A logical next step would be to design and implement studies to measure impact on quality of life by including a control arm and increasing the sample size. The evidence this would create is necessary to ensure that the potential benefits are indeed realisable, and thereby move forward towards clinical implementation. The sensor data generated through a larger, controlled study design would be highly valuable for future development iterations of the technological setup to support dementia rehabilitation. In particular, aiding the development of algorithms for detection or prediction of behavioural traits or patterns that warrant intervention, thereby advancing predictive and preventative care.

While employing a holistic, system-view this thesis has focused on the role of technology within this, since it is primarily the introduction of new technologies into the system that is examined in this work. Evaluating the novel solution developed for mobile/wearable technology to support rehabilitation in a real-life setup among the target population has contributed towards an understanding of what clinical implementation in practice might entail. Next, it is of interest to extend this implementation to more closely replicate a full rehabilitation intervention. This would include, for example, greater input from a healthcare professional in defining and following goals with participants, and the inclusion of feedback from the behavioural monitoring to facilitate their interaction. This more detailed look at clinical implementation would resolve some of the many unknown issues towards integration into care delivery in practice.

The need for technological developments large and small are also noted. The evaluation study (section 5.2, published in [20]) documents issues regarding compatibility, the reliability of gathering data from a connected wearable device, and usability.

Finally, the procedure for documenting compliance with data protection regulations was particularly challenging in planning the study itself. This stemmed from uncertainty from regulatory authorities regarding the approval process for research merging data from clinical sources and personal devices. Such obstacles are anticipated when entering new territories, and will be necessary to overcome in future research of this nature. The challenges associated with establishing appropriate regulatory frameworks/procedures can be extended to include those of creating infrastructures for secure data flow and of integrating novel data sources into existing healthcare information systems in place today.

6.5 Conclusions and reflections

This PhD project set out to examine the role of mobile and wearable technology in healthcare systems for supporting both patient quality of life and care practices, specifically within the context of dementia. Through a series of three main objectives, this thesis has explored what this role might entail, developed technology for its fulfilment, and implemented the solution in a real-life context to evaluate its potential benefits in clinical practice. What has been learnt in the process expands beyond these three steps. This research process has taught of the day-to-day lives of elderly, cognitively impaired people, what quality of life means for them – and how varied this is even among a handful of individuals. It has taught of the complexity of dementia care: the many unknowns that healthcare professionals face in gathering information to make decisions, the many roles played, interdependencies between actors, and coordination required. It has taught about what technology might offer, and what it cannot, how users interact with the technology presented to them and what motivates them to do so. This work has endeavoured to gather these many subtle nuances into a coherent message in this thesis. In simplest terms, this message that there is potential for new technologies to benefit dementia care. This benefit arises from a dual-purpose: it could enhance quality of life among people with dementia through personalised support in everyday life, and it could provide a means of objective, continuous behavioural monitoring for more proactive care approaches. The technology examined specifically includes personal mobile and wearable devices, e.g. smartphones and smartwatches. This was motivated by their growing popularity which makes them a promising platform in terms of user acceptance – a common challenge among assistive technologies for dementia – and for broadening access to care. Embarking on this PhD project, the idea was that technology such as smartphones or wearables present interesting opportunities for support in dementia care that were worth pursuing in case at least some people could benefit from these. On reflection at the end of this project, this perspective has changed. The use of smartphones for support among people with dementia is not just an opportunity – it is an inevitability. Smartphones and wearables are rapidly becoming integrated into the running of our everyday lives irrespective of our health status. Participants in this research who rely on these devices to structure their lives and manage incoming information are highly representative of the future elderly population. This work has taken an important step towards preparing for this future by understanding the role of emerging technologies in healthcare practices, and actively investigating how best to leverage their capabilities to benefit the wider system and all actors involved.

References

[1] J. R. Thorpe, K. V. H. Rønn-Andersen, P. Bień, A. G. Özkil, B. H. Forchhammer, and A. M. Maier, "Pervasive assistive technology for people with dementia: a UCD case," *Healthc. Technol. Lett.*, Oct. 2016.

[2] B. Rechel, Y. Doyle, E. Grundy, and M. Mckee, "How can health systems respond to population ageing?," 2009.

[3] B. C. Spillman and J. Lubitz, "The Effect of Longevity on Spending for Acute and Long-Term Care," *N. Engl. J. Med.*, vol. 342, no. 19, pp. 1409–1415, May 2000.

[4] L. Hood, "A systems approach to medicine will transform healthcare," *Phys. Biol. From Atoms To Med.*, 2008.

[5] M. Swan, "Health 2050: The Realization of Personalized Medicine through Crowdsourcing, the Quantified Self, and the Participatory Biocitizen," *J. Pers. Med.*, vol. 2, no. 4, pp. 93–118, 2012.

[6] Royal Academy of Engineering, Academy of Medical Sciences, and Royal College of Physicians, "Engineering better care: a systems approach to health and care design and continuous improvement," 2017.

[7] D. de Savigny and T. Adam, "Systems Thinking for Health Systems Strengthening," World Health Organization, 2017.

[8] W. B. Rouse and D. A. Cortese, *Engineering the system of healthcare delivery*. IOS Press, 2010.

[9] F. Patou and A. Maier, "Engineering Value-Effective Healthcare Solutions: A Systems Design Perspective," in *Proceedings of the 21st International Conference on Engineering Design (ICED17), Vol. 3: Product, Services and Systems Design*, Design Society, 2017, pp. 31–41.

[10] A. Khan and J. Madden, "Mobile Devices as a Resource in Gathering Health Data: The Role of Mobile Devices in the Improvement of Global Health," in *2016 International Conference on Computational Science and Computational Intelligence (CSCI)*, 2016, pp. 1010–1015.

[11] C. S. Kruse, R. Goswamy, Y. Raval, and S. Marawi, "Challenges and Opportunities of Big Data in Health Care: A Systematic Review.," *JMIR Med. informatics*, vol. 4, no. 4, p. e38, Nov. 2016.

[12] E. J. Topol, "Individualized medicine from prewomb to tomb," *Cell*, vol. 157, no. 1, pp. 241–253, 2014.

[13] "WHO | Global action plan on the public health response to dementia 2017 - 2025," *WHO*, 2017.

[14] C. K. Cassel, "Aging: Adding complexity, requiring skills," *Stud. Health Technol. Inform.*, vol. 153, 2010.

[15] A. Bahar-Fuchs, L. Clare, and B. Woods, "Cognitive training and cognitive rehabilitation for mild to moderate Alzheimer's disease and vascular dementia.," *Cochrane database Syst. Rev.*, vol. 6, p. CD003260, Jan. 2013.

[16] L. T. M. Blessing and A. Chakrabarti, *DRM, a Design Research Methodology*. 2009.

[17] J. R. Thorpe, B. H. Forchhammer, and A. M. Maier, "Development of a sensor-based behavioural monitoring solution to support dementia care," *JMIR Prepr.*, 2018.

[18] J. Thorpe, K. Rønn-Andersen, P. Bien, A. Özkil, B. Forchhammer, and A. Maier, "Pervasive assistive technology for people with dementia: a user-centred design case," *Healthc. Technol. Lett.*, Oct. 2016.

[19] J. E. Bardram, "CACHET Unified Methodology for Assessment of Clinical Feasibility: Establishing clinical evidence for the feasibility of personal health technology during design, development, and pilot testing," 2018.

[20] Thorpe JR, Forchhammer BH, and Maier A, "Adapting mobile and wearable technology to provide support and monitoring in rehabilitation for dementia: a feasibility study," *JMIR Prepr.* , 2018.

[21] J. R. Thorpe, B. H. Forchhammer, and A. Maier, "Sensing behaviour in healthcare design," in *Proceedings of the 21st International Conference on Engineering Design (ICED17), Vol. 3: Product, Services and Systems Design*, 2017, pp. 171–181.

[22] D. de Savigny, T. Adam, Alliance for Health Policy and Systems Research, and World Health Organization, "Systems Thinking for Health Systems Strengthening," World Health Organization, 2009.

[23] O. L. De Weck, D. Roos, C. L. Magee, C. M. Vest, and C. M. Cooper, *Engineering Systems: Meeting Human Needs in a Complex Technological World*, 1st ed. Cambridge, MA: MIT Press, 2011.

[24] W. B. Rouse, "Health Care as a Complex Adaptive System : Implications for Design and Management," *Organ. Sci.*, 2008.

[25] W. B. Rouse and N. Serban, *Understanding and managing the complexity of healthcare*. 2014.

[26] E. C. Nelson *et al.*, "Microsystems in health care: Part 1. Learning from high-performing front-line clinical units.," *Jt. Comm. J. Qual. Improv.*, vol. 28, no. 9, pp. 472–93, Sep. 2002.

[27] C. K. Cassel, M. Johnston-Fleece, and S. Reddy, "Aging: Adding complexity, requiring skills," in *Studies in Health Technology and Informatics*, 2010.

[28] P. J. Clarkson *et al.*, "Design for patient safety: A review of the effectiveness of design in the UK health service," *J. Eng. Des.*, vol. 15, no. 2, pp. 123–140, Apr. 2004.

[29] P. John Clarkson and R. Coleman, "History of Inclusive Design in the UK.," *Appl. Ergon.*, vol. 46 Pt B, pp. 235–47, Jan. 2015.

[30] J. Clarkson and R. Coleman, "Inclusive design," *J. Eng. Des.*, vol. 21, no. 2, pp. 127–129, Apr. 2010.

[31] L. De Couvreur and R. Goossens, "Design for (every)one: co-creation as a bridge between universal design and rehabilitation engineering," *CoDesign*, vol. 7, no. 2, pp. 107–121, Jun. 2011.

[32] W. W. Stead, "Electronic health records," *Inf. Knowl. Syst. Manag.*, vol. 8, no. 1–4, 2009.

[33] I. Korhonen and Bardram, J.E., "Guest editorial introduction to the special section on pervasive healthcare," *IEEE Trans. Inf. Technol. Biomed.*, vol. 8, pp. 229–234, 2004.

[34] R. Bashshur, G. Shannon, E. Krupinski, and J. Grigsby, "The Taxonomy of Telemedicine," *Telemed. e-Health*, vol. 17, no. 6, pp. 484–494, Jul. 2011.

[35] S. R. Steinhubl, E. D. Muse, and E. J. Topol, "The emerging field of mobile health.," *Sci. Transl. Med.*, vol. 7, no. 283, p. 283rv3, Apr. 2015.

[36] M. D. . b Majmudar, L. A. . Colucci, and A. B. . d Landman, “The quantified patient of the future: Opportunities and challenges,” *Healthcare*, 2015.

[37] M. Swan, “Sensor Mania! The Internet of Things, Wearable Computing, Objective Metrics, and the Quantified Self 2.0,” *J. Sens. Actuator Networks*, vol. 1, pp. 217–253, 2012.

[38] J. E. Bardram, “Pervasive healthcare as a scientific discipline.,” *Methods Inf. Med.*, vol. 47, no. 3, pp. 178–85, Jan. 2008.

[39] J. E. Bardram, A. Mihailidis, and D. Wan, *Pervasive computing in healthcare*. Taylor & Francis, 2007.

[40] J. E. Bardram and M. M. Frost, “Double-Loop Health Technology,” in *Designing Healthcare That Works*, Elsevier, 2018, pp. 167–186.

[41] J. E. Bardram and M. Frost, “The Personal Health Technology Design Space,” *IEEE Pervasive Comput.*, vol. 15, no. 2, pp. 70–78, Apr. 2016.

[42] N. Eagle and A. Pentland, “Reality mining: Sensing complex social systems,” *Pers. Ubiquitous Comput.*, vol. 10, no. 4, pp. 255–268, 2006.

[43] N. Eagle, A. S. Pentland, and D. Lazer, “Inferring friendship network structure by using mobile phone data.,” *Proc. Natl. Acad. Sci. U. S. A.*, vol. 106, no. 36, pp. 15274–15278, 2009.

[44] A. Stopczynski *et al.*, “Measuring large-scale social networks with high resolution.,” *PLoS One*, vol. 9, no. 4, p. e95978, 2014.

[45] T. Aledavood, S. Lehmann, and J. Saramäki, “Digital daily cycles of individuals,” *Front. Phys.*, vol. 3, 2015.

[46] L. Canzian and M. Musolesi, “Trajectories of Depression: Unobtrusive Monitoring of Depressive States by means of Smartphone Mobility Traces Analysis.”

[47] J. Y. Tung *et al.*, “Measuring life space in older adults with mild-to-moderate Alzheimer’s disease using mobile phone GPS.,” *Gerontology*, vol. 60, no. 2, pp. 154–162, Jan. 2014.

[48] J. Tung, J. Semple, W. Woo, and W. Hsu, “Ambulatory Assessment of Lifestyle Factors for Alzheimer’s Disease and Related Dementias,” *AAAI Spring Symp. …*, pp. 50–54, 2011.

[49] J. Liddle *et al.*, “Measuring the Lifespace of People With Parkinson ’ s Disease Using Smartphones : Proof of Principle Corresponding Author :,” *JMIR mHealth uHealth*, vol. 2, 2014.

[50] J. Morris, J. Mueller, and M. Jones, “Tomorrow’s elders with disabilities: what the wireless industry needs to know,” *J. Eng. Des.*, vol. 21, no. February 2015, pp. 131–146, 2010.

[51] L. Clare *et al.*, “Goal-oriented cognitive rehabilitation in early-stage dementia: study protocol for a multi-centre single-blind randomised controlled trial (GREAT).,” *Trials*, vol. 14, p. 152, Jan. 2013.

[52] M. Prince, A. Wimo, M. Guerchet, A. Gemma-Claire, Y.-T. Wu, and M. Prina, “World Alzheimer Report 2015: The Global Impact of Dementia - An analysis of prevalence, incidence, cost and trends,” *Alzheimer’s Dis. Int.*, p. 84, 2015.

[53] Nationalt Videnscenter for Demens, “Tal og statistik om demens - NVD.” [Online]. Available: http://www.videnscenterfordemens.dk/viden-om-demens/tal-og-statistik-om-demens/. [Accessed: 09-Jan-2015].

[54] T. L. The Lancet Neurology, "Response to the growing dementia burden must be faster.," *Lancet. Neurol.*, vol. 17, no. 8, p. 651, Aug. 2018.

[55] "Dansk Klinisk Kvalitetsdatabase for Demens Årsrapport 2016," 2016.

[56] M. Huckans, L. Hutson, E. Twamley, A. Jak, J. Kaye, and D. Storzbach, "Efficacy of cognitive rehabilitation therapies for mild cognitive impairment (MCI) in older adults: working toward a theoretical model and evidence-based interventions.," *Neuropsychol. Rev.*, vol. 23, no. 1, pp. 63–80, Mar. 2013.

[57] D. T. Wade, "Describing rehabilitation interventions," *Clin. Rehabil.*, vol. 19, no. 8, pp. 811–818, Dec. 2005.

[58] B. A. Wilson, "Towards a comprehensive model of cognitive rehabilitation," *Neuropsychol. Rehabil.*, vol. 12, no. 2, pp. 97–110, Mar. 2002.

[59] D. T. Wade and B. A. de Jong, "Recent advances in rehabilitation.," *BMJ*, vol. 320, no. 7246, pp. 1385–8, May 2000.

[60] L. Evald, "Prospective memory rehabilitation using smartphones in patients with TBI," *Disabil. Rehabil.*, vol. 40, no. 19, pp. 2250–2259, Sep. 2018.

[61] J. Klonovs *et al.*, "Monitoring Technology," Springer, Cham, 2016, pp. 49–84.

[62] M. Sagner *et al.*, "The P4 Health Spectrum – A Predictive, Preventive, Personalized and Participatory Continuum for Promoting Healthspan," *Prog. Cardiovasc. Dis.*, vol. 59, no. 5, pp. 506–521, 2017.

[63] L. Hood, R. Balling, and C. Auffray, "Revolutionizing medicine in the 21st century through systems approaches," *Biotechnol. J.*, vol. 7, no. 8, pp. 992–1001, 2012.

[64] M. Flores, G. Glusman, K. Brogaard, N. D. Price, and L. Hood, "P4 medicine: how systems medicine will transform the healthcare sector and society," *Per. Med.*, vol. 10, no. 6, pp. 565–576, Aug. 2013.

[65] A. D. Westont and L. Hood, "Systems Biology, Proteomics, and the Future of Health Care: Toward Predictive, Preventative, and Personalized Medicine," *J. Proteome Res.*, vol. 3, no. 2, pp. 179–196, 2004.

[66] L. Hood and C. Auffray, "Participatory medicine: A driving force for revolutionizing healthcare," *Genome Medicine*, vol. 5, no. 12, p. 110, 2013.

[67] E. Mattila, I. Korhonen, and N. Saranummi, "Mobile and personal health and wellness management systems," in *Pervasive Computing in Healthcare*, 2007, pp. 105–134.

[68] G. E. Lancioni *et al.*, "Persons with moderate Alzheimer's disease use simple technology aids to manage daily activities and leisure occupation.," *Res. Dev. Disabil.*, vol. 35, no. 9, pp. 2117–2128, Sep. 2014.

[69] A. Mihailidis, J. N. Boger, T. Craig, and J. Hoey, "The COACH prompting system to assist older adults with dementia through handwashing: an efficacy study.," *BMC Geriatr.*, vol. 8, p. 28, 2008.

[70] S. Bjorneby, "Ethical Considerations in the ENABLE Project," *Dementia*, vol. 3. pp. 297–312, 2004.

[71] V. Perilli *et al.*, "A computer-aided telephone system to enable five persons with Alzheimer's

disease to make phone calls independently," *Res. Dev. Disabil.*, vol. 34, no. 6, pp. 1991–1997, Jun. 2013.

[72] B. J. J. Hattink *et al.*, "The electronic, personalizable Rosetta system for dementia care: exploring the user-friendliness, usefulness and impact.," *Disabil. Rehabil. Assist. Technol.*, pp. 1–11, Jul. 2014.

[73] L. Robinson, K. Brittain, S. Lindsay, D. Jackson, and P. Olivier, "Keeping In Touch Everyday (KITE) project: developing assistive technologies with people with dementia and their carers to promote independence.," *Int. Psychogeriatr.*, vol. 21, no. 3, pp. 494–502, Jun. 2009.

[74] D. Patterson, L. Liao, H. Kautz, and D. Fox, "Pervasive computing in the home and community," in *Pervasive Computing in Healthcare*, CRC Press, 2006, pp. 79–103.

[75] G. De Leo, E. Brivio, and S. W. Sautter, "Supporting autobiographical memory in patients with Alzheimer's disease using smart phones.," *Appl. Neuropsychol.*, vol. 18, no. 1, pp. 69–76, Jan. 2011.

[76] B. Kikhia, J. Hallberg, K. K. Synnes, and Z. ul H. Sani, "Context-aware life-logging for persons with mild dementia.," *Conf. Proc. ... Annu. Int. Conf. IEEE Eng. Med. Biol. Soc. IEEE Eng. Med. Biol. Soc. Annu. Conf.*, vol. 2009, pp. 6183–6186, 2009.

[77] H. M. Fardoun, A. A. Mashat, and J. Ramirez Castillo, "Recognition of familiar people with a mobile cloud architecture for Alzheimer patients.," *Disabil. Rehabil.*, pp. 1–5, Mar. 2015.

[78] K. Garland, E. Beer, B. Eppingstall, and D. W. O'Connor, "A comparison of two treatments of agitated behavior in nursing home residents with dementia: simulated family presence and preferred music.," *Am. J. Geriatr. Psychiatry*, vol. 15, no. 6, pp. 514–521, Jun. 2007.

[79] T. Shibata and K. Wada, "Robot therapy: A new approach for mental healthcare of the elderly - A mini-review," *Gerontology*, vol. 57, no. 4, pp. 378–386, 2011.

[80] C. Kerssens *et al.*, "Personalized Technology to Support Older Adults With and Without Cognitive Impairment Living at Home.," *Am. J. Alzheimers. Dis. Other Demen.*, vol. 30, no. 1, pp. 85–97, Jan. 2015.

[81] V. Leuty, J. Boger, L. Young, J. Hoey, and A. Mihailidis, "Engaging older adults with dementia in creative occupations using artificially intelligent assistive technology.," *Assist. Technol.*, vol. 25, no. 2, pp. 72–79, 2013.

[82] A. Lazar, H. Thompson, and G. Demiris, "A systematic review of the use of technology for reminiscence therapy.," *Health Educ. Behav.*, vol. 41, no. 1 Suppl, p. 51S–61S, Oct. 2014.

[83] M. Schwenk, K. Hauer, and T. Zieschang, "Sensor-Derived Physical Activity Parameters Can Predict Future Falls in People with Dementia," *Gerontology*, vol. 60, no. 6, pp. 483–492, 2014.

[84] T. Adlam, R. Faulkner, R. Orpwood, K. Jones, J. Macijauskiene, and A. Budraitiene, "The installation and support of internationally distributed equipment for people with dementia," *IEEE Trans. Inf. Technol. Biomed.*, vol. 8, no. 3, pp. 253–257, Sep. 2004.

[85] A. Olsson, M. Engstrom, C. Lampic, and K. Skovdahl, "A passive positioning alarm used by persons with dementia and their spouses--a qualitative intervention study.," *BMC Geriatr.*, vol. 13, p. 11, 2013.

[86] F. . Cavallo, M. . Aquilano, and M. . Arvati, "An ambient assisted living approach in designing domiciliary services combined with innovative technologies for patients with alzheimer's

disease: A case study," *Am. J. Alzheimers. Dis. Other Demen.*, vol. 30, no. 1, pp. 69–77, 2015.

[87] S. Lundberg, "The results from a two-year case study of an information and communication technology support system for family caregivers.," *Disabil. Rehabil. Assist. Technol.*, vol. 9, no. 4, pp. 353–358, Jul. 2014.

[88] N. Shoval *et al.*, "The use of advanced tracking technologies for the analysis of mobility in Alzheimer's disease and related cognitive diseases.," *BMC Geriatr.*, vol. 8, p. 7, 2008.

[89] H. Aloulou *et al.*, "Deployment of assistive living technology in a nursing home environment: methods and lessons learned.," *BMC Med. Inform. Decis. Mak.*, vol. 13, p. 42, 2013.

[90] G. Sacco *et al.*, "Detection of activities of daily living impairment in Alzheimer's disease and mild cognitive impairment using information and communication technology.," *Clin. Interv. Aging*, vol. 7, pp. 539–549, 2012.

[91] S. Czarnuch, S. Cohen, V. Parameswaran, and A. Mihailidis, "A real-world deployment of the COACH prompting system," *J. Ambient Intell. Smart Environ.*, vol. 5, no. 5, pp. 463–478, 2013.

[92] C. Peters, T. Hermann, S. Wachsmuth, and J. Hoey, "Automatic Task Assistance for People with Cognitive Disabilities in Brushing Teeth - A User Study with the TEBRA System," *ACM Trans. Access. Comput.*, vol. 5, no. 4, pp. 1–34, Mar. 2014.

[93] M. W. Bewernitz, W. C. Mann, P. Dasler, and P. Belchior, "Feasibility of machine-based prompting to assist persons with dementia.," *Assist. Technol.*, vol. 21, no. 4, pp. 196–207, Jan. 2009.

[94] Y.-J. Y.-J. . Chang, T.-Y. T.-Y. . Wang, and Y.-R. Y.-R. . Chen, "A location-based prompting system to transition autonomously through vocational tasks for individuals with cognitive impairments," *Res. Dev. Disabil.*, vol. 32, no. 6, pp. 2669–2673, Jan. 2011.

[95] H. H. Imbeault *et al.*, "Electronic organiser and Alzheimer's disease: fact or fiction?," *Neuropsychol. Rehabil.*, vol. 24, no. 1, pp. 71–100, Jan. 2014.

[96] J. . c Augusto *et al.*, "Night optimised care technology for users needing assisted lifestyles," *Behav. Inf. Technol.*, vol. 33, no. 12, pp. 1261–1277, 2014.

[97] A. O. Caffo *et al.*, "Comparing two different orientation strategies for promoting indoor traveling in people with Alzheimer's disease," *Res. Dev. Disabil.*, vol. 35, no. 2, pp. 572–580, Feb. 2014.

[98] O. Mäki and P. Topo, "User needs and user requirements of people with dementia: Multimedia application for entertainment," *Assist. technol. Res. Ser.*, vol. 24, pp. 61–75, 2009.

[99] F. Y. Leng, D. Yeo, S. George, and C. Barr, "Comparison of iPad applications with traditional activities using person-centred care approach: impact on well-being for persons with dementia.," *Dementia*, vol. 13, no. 2, pp. 265–273, Mar. 2014.

[100] T. Damianakis, M. Crete-Nishihata, K. L. Smith, R. M. Baecker, and E. Marziali, "The psychosocial impacts of multimedia biographies on persons with cognitive impairments.," *Gerontologist*, vol. 50, no. 1, pp. 23–35, Feb. 2010.

[101] M. Massimi, E. Berry, G. Browne, G. Smyth, P. Watson, and R. M. Baecker, "An exploratory case study of the impact of ambient biographical displays on identity in a patient with Alzheimer's disease.," *Neuropsychol. Rehabil.*, vol. 18, no. 5–6, pp. 742–765, 2008.

[102] B. A. Purves, A. Phinney, W. Hulko, G. Puurveen, and A. J. Astell, "Developing CIRCA-BC

and exploring the role of the computer as a third participant in conversation.," *Am. J. Alzheimers. Dis. Other Demen.*, vol. 30, no. 1, pp. 101–7, Feb. 2015.

[103] C. C. Lin, M. J. Chiu, C. C. Hsiao, R. G. Lee, and Y. S. Tsai, "Wireless health care service system for elderly with dementia," *IEEE Trans. Inf. Technol. Biomed.*, vol. 10, pp. 696–704, 2006.

[104] M. A. Rowe *et al.*, "Reducing dangerous nighttime events in persons with dementia by using a nighttime monitoring system.," *Alzheimers. Dement.*, vol. 5, no. 5, pp. 419–426, Sep. 2009.

[105] D. Holmes *et al.*, "An evaluation of a monitoring system intervention: falls, injuries, and affect in nursing homes.," *Clin. Nurs. Res.*, vol. 16, no. 4, pp. 317–335, Nov. 2007.

[106] W. D. Kearns *et al.*, "Path tortuosity in everyday movements of elderly persons increases fall prediction beyond knowledge of fall history, medication use, and standardized gait and balance assessments.," *J. Am. Med. Dir. Assoc.*, vol. 13, no. 7, p. 665.e7-665.e13, Sep. 2012.

[107] A. E. Tchalla *et al.*, "Preventing and Managing Indoor Falls with Home-Based Technologies in Mild and Moderate Alzheimer's Disease Patients: Pilot Study in a Community Dwelling," *Dement. Geriatr. Cogn. Disord.*, vol. 36, no. 3–4, pp. 251–261, 2013.

[108] L. J. Hayden, S. M. Glynn, T. J. Hahn, F. Randall, and E. Randolph, "The use of Internet technology for psychoeducation and support with dementia caregivers.," *Psychol. Serv.*, vol. 9, no. 2, pp. 215–218, May 2012.

[109] D. W. K. Man, S. F. Tam, and C. W. Y. Hui-Chan, "Learning to live independently with expert systems in memory rehabilitation," *NeuroRehabilitation*, vol. 18, no. 1, pp. 21–29, 2002.

[110] A. König *et al.*, "Validation of an automatic video monitoring system for the detection of instrumental activities of daily living in dementia patients.," *J. Alzheimers. Dis.*, vol. 44, no. 2, pp. 675–85, Jan. 2015.

[111] U. Lindemann, Ed., *Human Behaviour in Design*. Berlin, Heidelberg: Springer Berlin Heidelberg, 2003.

[112] P. J. Cash, C. G. Hartlev, and C. B. Durazo, "Behavioural design: A process for integrating behaviour change and design," *Des. Stud.*, pp. 1–33, 2016.

[113] I. Behoora and C. S. Tucker, "Machine learning classification of design team members' body language patterns for real time emotional state detection," *Des. Stud.*, vol. 39, pp. 100–127, 2015.

[114] M. Steinert and K. Jablokow, "Triangulating front end engineering design activities with physiology data and psychological preferences," *DS 75-7: Proceedings of the 19th International Conference on Engineering Design (ICED13), Design for Harmonies, Vol.7: Human Behaviour in Design, Seoul, Korea, 19-22.08.2013*. p. 576, 2013.

[115] G. Aldaz, M. Steinert, and L. J. Leifer, "Instrumenting the user: Needfinding by combining data logging and immediate self-reporting," *DS 75-7: Proceedings of the 19th International Conference on Engineering Design (ICED13), Design for Harmonies, Vol.7: Human Behaviour in Design, Seoul, Korea, 19-22.08.2013*. p. 576, 2013.

[116] K. Thoring, R. M. Mueller, and P. Badke-Schaub, "Technology-Supported Design Research," *Int. Conf. Eng. Des. ICED15*, no. July, pp. 1–10, 2015.

[117] M. Chan, D. Estève, J.-Y. Fourniols, C. Escriba, and E. Campo, "Smart wearable systems: current status and future challenges.," *Artif. Intell. Med.*, vol. 56, no. 3, pp. 137–56, Nov. 2012.

[118] M. Fiordelli, N. Diviani, and P. J. Schulz, "Mapping mHealth research: a decade of evolution.," *J. Med. Internet Res.*, vol. 15, no. 5, p. e95, May 2013.

[119] H. Xiong, Y. Huang, L. E. Barnes, and M. S. Gerber, "Sensus: A Cross-platform, General-purpose System for Mobile Crowdsensing in Human-subject Studies," *Proc. 2016 ACM Int. Jt. Conf. Pervasive Ubiquitous Comput.*, pp. 415–426, 2016.

[120] E. Giannouli, O. Bock, S. Mellone, and W. Zijlstra, "Mobility in old age: Capacity is not performance," *Biomed Res. Int.*, vol. 2016, 2016.

[121] L. Canzian and M. Musolesi, *Trajectories of Depression: Unobtrusive Monitoring of Depressive States by means of Smartphone Mobility Traces Analysis*. New York, New York, USA: ACM Press, 2015, pp. 1293–1304.

[122] A. Cuttone, S. Lehmann, and J. E. Larsen, "Inferring human mobility from sparse low accuracy mobile sensing data," *Proc. 2014 ACM Int. Jt. Conf. Pervasive Ubiquitous Comput. Adjun. Publ. - UbiComp '14 Adjun.*, pp. 995–1004, 2014.

[123] Y. Huang *et al.*, *Assessing Social Anxiety using GPS Trajectories and Point-Of-Interest Data*. New York, New York, USA: ACM Press, 2016, pp. 898–903.

[124] N. Eagle and A. S. Pentland, "Eigenbehaviors: Identifying structure in routine," *Behav. Ecol. Sociobiol.*, vol. 63, no. 7, pp. 1057–1066, 2009.

[125] J. Ahn and R. Han, "Personalized behavior pattern recognition and unusual event detection for mobile users," *Mob. Inf. Syst.*, vol. 9, no. 2, pp. 99–122, 2013.

[126] M. del Rosario, S. Redmond, and N. Lovell, "Tracking the Evolution of Smartphone Sensing for Monitoring Human Movement," *Sensors*, vol. 15, no. 8, pp. 18901–18933, Jul. 2015.

[127] S. van der Weegen, R. Verwey, M. Spreeuwenberg, H. Tange, T. van der Weijden, and L. de Witte, "The development of a mobile monitoring and feedback tool to stimulate physical activity of people with a chronic disease in primary care: a user-centered design.," *JMIR mHealth uHealth*, vol. 1, no. 2, p. e8, Jul. 2013.

[128] A. Derungs, J. Seiter, C. Schuster-Amft, and O. Amft, *Activity Patterns in Stroke Patients -Is There a Trend in Behaviour During Rehabilitation?* Springer International Publishing, 2015, pp. 146–159.

[129] G. Sprint, D. J. Cook, and M. Schmitter-Edgecombe, "Unsupervised detection and analysis of changes in everyday physical activity data," 2016.

[130] A. Paraschiv-Ionescu *et al.*, *Patterns of Human Activity Behavior: From Data to Information and Clinical Knowledge*, vol. 23. New York, New York, USA: ACM Press, 2016, pp. 841–845.

[131] B. Guo, S. Yang, J. Lindqvist, X. Xie, and R. K. Ganti, "Guest Editorial Special Issue on Mobile Crowd Sensing for IoT," *IEEE Internet Things J.*, vol. 2, no. 5, pp. 355–357, Oct. 2015.

[132] S. Jongstra, L. W. Wijsman, R. Cachucho, M. P. Hoevenaar-Blom, S. P. Mooijaart, and E. Richard, "Cognitive Testing in People at Increased Risk of Dementia Using a Smartphone App: The iVitality Proof-of-Principle Study.," *JMIR mHealth uHealth*, vol. 5, no. 5, p. e68, May 2017.

[133] N. Shoval *et al.*, "Use of the global positioning system to measure the out-of-home mobility of older adults with differing cognitive functioning," *Ageing Soc.*, vol. 31, no. 5, pp. 849–869, Jul. 2011.

[134] A. L. Rosso, J. A. Taylor, L. P. Tabb, and Y. L. Michael, "Mobility, disability, and social engagement in older adults," *J. Aging Health*, vol. 25, no. 4, pp. 617–637, 2013.

[135] S. C. Webber, M. M. Porter, and V. H. Menec, "Mobility in older adults: A comprehensive framework," *Gerontologist*, vol. 50, no. 4, pp. 443–450, 2010.

[136] S. Werner, G. K. Auslander, N. Shoval, T. Gitlitz, R. Landau, and J. Heinik, "Caregiving burden and out-of-home mobility of cognitively impaired care-recipients based on GPS tracking.," *Int. Psychogeriatr.*, vol. 24, no. 11, pp. 1836–1845, Nov. 2012.

[137] J. Y. Tung *et al.*, "Measuring life space in older adults with mild-to-moderate Alzheimer's disease using mobile phone GPS.," *Gerontology*, vol. 60, no. 2, pp. 154–162, 2014.

[138] G. Livingston *et al.*, "Dementia prevention, intervention, and care," *Lancet*, vol. 390, no. 10113, pp. 2673–2734, Dec. 2017.

[139] M. Wettstein *et al.*, "Out-of-home behavior and cognitive impairment in older adults: findings of the SenTra Project.," *J. Appl. Gerontol.*, vol. 34, no. 1, pp. 3–25, Feb. 2015.

[140] C. Rye Hanton *et al.*, "Mobile Phone-Based Measures of Activity, Step Count, and Gait Speed: Results From a Study of Older Ambulatory Adults in a Naturalistic Setting.," *JMIR mHealth uHealth*, vol. 5, no. 10, p. e104, Oct. 2017.

[141] B. Zylstra *et al.*, "Extended, continuous measures of functional status in community dwelling persons with Alzheimer's and related dementia: Infrastructure, performance, tradeoffs, preliminary data, and promise," *J. Neurosci. Methods*, vol. 300, pp. 59–67, Apr. 2018.

[142] L. Allet, R. H. Knols, K. Shirato, and E. D. de Bruin, "Wearable systems for monitoring mobility-related activities in chronic disease: a systematic review.," *Sensors (Basel).*, vol. 10, no. 10, pp. 9026–9052, 2010.

[143] P. Boissy *et al.*, "Wireless inertial measurement unit with GPS (WIMU - GPS) – Wearable monitoring platform for ecological assessment of lifespace and mobility in aging and disease," in *IEEE Engineering in Medicine and Biology Magazine*, 2011, pp. 5815–5819.

[144] J. A. Hirsch, M. Winters, P. Clarke, and H. Mckay, "Generating GPS activity spaces that shed light upon the mobility habits of older adults : a descriptive analysis," *Int. J. Health Geogr.*, pp. 1–14, 2014.

[145] Y. Zheng, L. Zhang, X. Xie, and W.-Y. Ma, "Mining interesting locations and travel sequences from GPS trajectories," *Proc. 18th Int. Conf. World wide web - WWW '09*, no. 49, p. 791, 2009.

[146] G. Andrienko, N. Andrienko, G. Fuchs, A. M. Olteanu Raimond, J. Symanzik, and C. Ziemlicki, "Extracting Semantics of Individual Places from Movement Data by Analyzing Temporal Patterns of Visits," in *Proceedings of The First ACM SIGSPATIAL International Workshop on Computational Models of Place - COMP '13*, 2013, pp. 9–16.

[147] D. Ireland, S. McBride, J. Liddle, and H. Chenery, "Towards quantifying the impact of Parkinson's disease using GPS and lifespace assessment," in *2013 6th International Conference on Biomedical Engineering and Informatics*, 2013, pp. 564–569.

[148] M. Wettstein, H.-W. Wahl, N. Shoval, G. Auslander, F. Oswald, and J. Heinik, "Cognitive status moderates the relationship between out-of-home behavior (OOHB), environmental mastery and affect.," *Arch. Gerontol. Geriatr.*, vol. 59, no. 1, pp. 113–121, 2014.

[149] M. Wettstein, H.-W. Wahl, N. Shoval, G. Auslander, F. Oswald, and J. Heinik, "Identifying

Mobility Types in Cognitively Heterogeneous Older Adults Based on GPS-Tracking," *J. Appl. Gerontol.*, vol. 34, no. 8, pp. 1001–1027, Dec. 2015.

[150] E. B. Hekler *et al.*, "Validation of Physical Activity Tracking via Android Smartphones Compared to ActiGraph Accelerometer: Laboratory-Based and Free-Living Validation Studies.," *JMIR mHealth uHealth*, vol. 3, no. 2, p. e36, Apr. 2015.

[151] A. Stopczynski *et al.*, "Measuring Large-Scale Social Networks with High Resolution," *PLoS One*, vol. 9, no. 4, p. e95978, Apr. 2014.

[152] P. J. Leese, "Communicating eHealth information within the dementia care service system," Technical University of Denmark, 2016.

[153] C. I. Martínez-Alcalá, P. Pliego-Pastrana, A. Rosales-Lagarde, J. S. Lopez-Noguerola, and E. M. Molina-Trinidad, "Information and Communication Technologies in the Care of the Elderly: Systematic Review of Applications Aimed at Patients With Dementia and Caregivers.," *JMIR Rehabil. Assist. Technol.*, vol. 3, no. 1, p. e6, May 2016.

[154] S. Lauriks *et al.*, "Review of ICT-based services for identified unmet needs in people with dementia," *Ageing Res. Rev.*, vol. 6, no. 3, pp. 223–246, Oct. 2007.

[155] H. M. LaMonica *et al.*, "Examining Internet and eHealth Practices and Preferences: Survey Study of Australian Older Adults With Subjective Memory Complaints, Mild Cognitive Impairment, or Dementia.," *J. Med. Internet Res.*, vol. 19, no. 10, p. e358, Oct. 2017.

[156] A. M. Maier, A. G. Özkil, M. M. Bang, B. Hysse Forchhammer, and B. H. Forchhammer, "Remember to remember: A feasibility study adapting wearable technology to the needs of people aged 65 and older with Mild Cognitive Impairment (MCI) and Alzheimer's Dementia," in *Proceedings of International Conference on Engineering Design (ICED 2015)*, 2015, vol. 1 BT-Pr, pp. 331–340.

[157] R. A. Stucki *et al.*, "A web-based non-intrusive ambient system to measure and classify activities of daily living.," *J. Med. Internet Res.*, vol. 16, no. 7, p. e175, Jan. 2014.

[158] B. E. Dicianno, G. Henderson, and B. Parmanto, "Design of Mobile Health Tools to Promote Goal Achievement in Self-Management Tasks," *JMIR mHealth uHealth*, vol. 5, no. 7, p. e103, Jul. 2017.

[159] J. M. Cogollor *et al.*, "Evolution of Cognitive Rehabilitation After Stroke From Traditional Techniques to Smart and Personalized Home-Based Information and Communication Technology Systems: Literature Review.," *JMIR Rehabil. Assist. Technol.*, vol. 5, no. 1, p. e4, Mar. 2018.

[160] L. Turner-Stokes, "Goal Attainment Scaling (GAS) in Rehabilitation A practical guide Further information and advice may be obtained from :," vol. 44, no. 0, pp. 1–14, 2009.

[161] P. S. Baker, E. V. Bodner, and R. M. Allman, "Measuring Life-Space Mobility in Community-Dwelling Older Adults," *J. Am. Geriatr. Soc.*, vol. 51, no. 11, pp. 1610–1614, Nov. 2003.

[162] F. C. Bull, T. S. Maslin, and T. Armstrong, "Global physical activity questionnaire (GPAQ): nine country reliability and validity study.," *J. Phys. Act. Health*, vol. 6, no. 6, pp. 790–804, Nov. 2009.

[163] F. D. Davis, "Perceived Usefulness, Perceived Ease of Use, and User Acceptance of Information Technology," *MIS Q.*, vol. 13, no. 3, p. 319, Sep. 1989.

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A. Article: Designing predictive, preventative, personalised and participatory (P4) healthcare systems: a review of status and open challenges

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SUMMARY REVIEW EDITING

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Designing predictive, preventive, personalised and participatory (P4) healthcare systems: a literature review on status and open challenges

Healthcare systems are large-scale, complex engineering systems facing challenges that demand systems thinking and engineering design methods. One such challenge is the paradigm shift towards proactive, decentralised healthcare delivery of the digital era, conceptualised in the P4 medicine framework of predictive, preventative, personalised and participatory care. This paper presents the P4 healthcare vision, highlighting the need for support in designing P4 healthcare systems. Zooming in on the example of dementia care, we review literature with two main objectives: (i) to describe progress in the design of healthcare interventions towards P4, pinpointing successes and challenges; and consequently (ii) to propose key focus areas for healthcare system design. A search of scientific literature yielded 708 articles, of which 30 were ultimately selected for analysis. Our results indicate that while decentralisation is well established; preventative, personalised and participatory care are only partially achieved, and predictive care is absent from the work reviewed. To realise the full potential of P4 healthcare, we propose three key focus areas for engineering design frameworks to advance healthcare: data-centrality, designing smarter systems, and understanding human behaviour.

Keywords **–** P4 Medicine, Systems Medicine, Dementia, Design for Elderly, Healthcare Improvement, Healthcare Design, Data-driven Design, Systems Thinking.

Relevance to Design Practice **–** This article presents designers with an overview and status of the P4 (predictive, preventive, personalised and participatory) healthcare vision. Key focus areas are put forward for the development of holistic design frameworks to support the design of healthcare systems, products and services.

Introduction

Systems thinking and engineering design methods are gaining attention in the healthcare sphere to tackle some of the challenges faced by our healthcare systems (Craig & Chamberlain, 2017; Doss, 2014; Kim, Myers, & Allen, 2017; Komashie & Clarkson, 2018; Ku & Rosen, 2016; Lamé, 2018; Patou & Maier, 2017). Healthcare policy-makers and care providers have started to realise that many obstacles such as process inefficiencies, budget limitations, increasing technology-adoption costs, and scarcity of care personnel (Cutler, Rosen, & Vijan, 2006; Spillman & Lubitz, 2000) could not be overcome without first acknowledging the complex and adaptive nature of healthcare systems (William B. Rouse & Serban, 2014). Our healthcare systems are, at various level of granularity (national, organisational, service), composed of manifold interdependent parts interacting in complex ways. Healthcare delivery involves, e.g. diverse patients, healthcare professionals, families, services, medical devices, electronic health records, clinics, hospitals, insurers. The number, variety and partial unpredictability of interactions between these components are such that holistic approaches are essential for addressing healthcare challenges (Christensen, Hasman, & Hunter, 2010; Royal

Academy of Engineering, 2017; WHO, 2009). Conceptualisation and implementation of solutions to these challenges requires frameworks and methodologies tailored to the complexity inherent to healthcare systems.

One of the biggest challenges facing healthcare systems today is the transformation from conventional care to new approaches that are emerging from technological advancements of the digital era. The P4 framework of Predictive, Preventative, Personalised and Participative healthcare and medicine, embodies envisioned care delivery of the future (Flores, Glusman, Brogaard, Price, & Hood, 2013). P4 healthcare demands new types of products, services and systems, the design of which is strained by considerations such as broad variation in users and their capabilities, a strict regulatory framework, unconfined use contexts and environments, and strong reliance on interdisciplinary collaboration between fields with distinct research styles. Inspired by both the growing recognition of design- and systems-thinking as pertinent approaches for ameliorating our current healthcare delivery model, and by the emergence of P4 healthcare, in this paper we call for input from the engineering design field to support and accelerate transformation of our healthcare systems. There are myriad concepts, guidelines or tools to support specific aspects of designing P4 healthcare, e.g. to ensure usability among a broad range of users (John Clarkson & Coleman, 2015), to involve users with impaired capabilities (Hendriks, Slegers, & Duysburgh, 2015; Tobiasson, Sundblad, Walldius, & Hedman, 2015), to enhance users' experience interacting with healthcare technology or services (Møller & Kettley, 2017; Mullaney, Pettersson, Nyholm, & Stolterman, 2012) or to create an appropriate technical infrastructure (Bardram & Frost, 2016). They do not constitute a comprehensive engineering design framework to facilitate P4 healthcare, yet, they provide building blocks towards a holistic engineering design framework for facilitating P4 healthcare. The aim of work reported in this paper is therefore to lay the foundations for such a framework by evaluating what progress has been made on the journey from conventional to P4 healthcare, and consequently, by identifying key areas to be developed. We approach this by systematically reviewing literature using the illustrative example of dementia care, with the following objectives for the paper:

Review and analyse literature to relate healthcare technology based interventions (products, services and/or systems) to characteristics of conventional and P4 healthcare.

Evaluate progress from conventional to P4 healthcare, identifying which elements are being achieved or lagging behind.

Infer on the potential shortcomings of available engineering design frameworks, methods and tools in facilitating the emergence of P4 healthcare.

In the remainder of this section, we introduce P4 healthcare and within that context dementia care as the case healthcare application for this work. The next section describes the research methods employed in the systematic review and analysis, followed by the results. We then discuss the results, focusing on each of the P's of P4 healthcare in turn as well as describing broader implications for design, and finally present concluding remarks.

A paradigm shift in healthcare

Today, healthcare systems are still predominantly tailored around the central, reactive, episodic and population-based (i.e. generic) care delivery model of conventional medicine (Hood, Balling, & Auffray, 2012). For this model, the main objective is to react promptly to solicitations from symptomatic patients, i.e. to diagnose, treat and rapidly dismiss patients suffering an acute condition, or to provide episodic support for the chronically ill. The scientific and technological disruptions of the past two decades are driving a paradigm-shift in this model, with a trajectory set towards the advent of a P4 medicine (Hood & Auffray, 2013; Hood et al., 2012; Sagner et al., 2017; Westont & Hood, 2004). Predictive, Preventative, Personalised and Participative (P4) medicine is deemed to emerge from the "confluence of a systems approach to medicine and from the digitalisation of medicine that creates the large data sets necessary to deal with the complexities of disease" (Hood et al., 2012). In other words, the P4 model promises proactive healthcare delivery, more focused on wellness and on the implementation of anticipatory measures for predicting and preventing diseases or their adverse consequences. This vision contrasts with the main objectives and strongholds of our present healthcare systems: reactivity and short-term efficiency of episodic care delivery. Conceptualised after the completion of the Human Genome Project, and related breakthroughs in DNA sequencing technologies, the P4 vision relies as much on progress in the Life Sciences as on the capabilities offered by novel Information and Communication Technologies including smartphones, smartwatches, wearables, data science and artificial intelligence. The concept of digitisation Hood et al. refer to is central in discussions on P4 medicine and the future of healthcare: it evokes the digital capture of health-related information, but also the algorithms and devices on which the vision of personalised medicine rely (Swan, 2012; Topol, 2014).

The emergence of this new paradigm has implications for the relevance of engineering design frameworks for guiding the design of healthcare systems. As technological advancement (among other factors) radically transforms healthcare products and services, the less sufficient our current design approaches become. It is therefore important to recognise how healthcare systems are changing and what the impact this has on their design if we are to develop engineering design frameworks to support this transformation.

Dementia care as an illustrative case

We decided to limit our investigation to those interventions targeting dementia and mild cognitive impairment (MCI) to provide a more manageable scope for the review, while offering a relevant sample of work. Dementia care offers an interesting and appropriate lens for our investigation into P4 healthcare. The lack of a known cure (for most types of dementia) and typically slow progression mean ongoing, long-term disease management for many affected. Due to the nature of symptoms of dementia and comorbidities associated with old age, such disease management tends to rely on input from more actors than the patient alone, i.e. their informal caregivers, adding complexity apt for participatory care models. Because the clinical conditions involved (e.g. MCI, Alzheimer's disease) are chronic, generally progressive, partly predictable and to some extent preventable, these are particularly suited for a P4 approach (Kivimäki & Batty, 2016; Norton, Matthews, Barnes, Yaffe, &

Brayne, 2014; Sabia et al., 2017). It is worth noting regarding "prevention" that while dementia is generally not preventable, prevention need not refer to the sole purpose of avoiding disease onset, but may indeed relate to strategies designed to limit the further progression of disease or eluding its negative consequences. In the case of dementia care, prevention takes on many forms: prevention of adverse events such as falls or wandering, preventing (or postponing) nursing home placement (e.g. through interventions that support independence and ageing-in-place), and prevention (or slowing) of disease progression. In the latter, lifestyle factors can play a significant role. Physical activity and cognitive stimulation are associated with delayed dementia onset, and a patient's quality of life may influence the impact of cognitive decline: a concerning feedback loop can occur in which dementia onset leads to depression and reclusiveness, resulting in reduced cognitive and social simulation, further accelerating the impact of cognitive decline, in turn aggravating depressive symptoms. In this way, interventions aimed at maintaining or enhancing quality of life can have higher-level goals regarding disease progression. This leads us to the point of personalisation. People with dementia vary broadly in terms of functional capacity and lifestyle, and each exhibit an individual set of the many possible symptoms associated with dementia. The consequent variation in needs and desires for individual wellbeing underscore the value of personalisation among this patient group.

Besides suitability for P4 healthcare approaches, dementia care presents an important case regarding societal impact. The current and expected impact of dementia worldwide is one of the most preoccupying figures in society today. More than 46.8 million people were living with dementia in 2015 (Prince et al., 2015). This number is expected to rise to more than 131.5 million by 2050. Adding to an incommensurate social and moral burden, the cost of dementia weighs heavy on our healthcare systems, with more than 1 trillion USD expected to be spent worldwide in 2018 alone.

Research Methods

The goal of the literature search was to find articles addressing the design of technology-based interventions for dementia or mild cognitive impairment. Interventions in this context could be products, systems, services or a combination thereof targeting actors in the dementia care network, such as people with dementia, their caregivers and healthcare professionals.

Literature search

The review method followed a systematic approach to searching, selecting and analysing articles, and is outlined in **Figure 1**. The SCOPUS scientific database was searched to find articles with a title, keywords or abstract containing the terms "design"; either "technology", "intervention" or "system"; and either "dementia" or "mild cognitive impairment". To enhance the relevance of the initial search results, the source was limited to a collection of quality journals within the fields of engineering, design, healthcare and medicine (see Appendix A). To deal with the extreme breadth of the term *technology*, which in this context refers to information and communication technology (ICT) of the digital era, the timeframe was restricted to articles published from 2007 onwards. This is based on the emergence of the term P4 medicine proposed by Hood in several publications from this period

(Hood, 2008; Price, Foltz, Madan, Hood, & Tian, 2008) (as a reference point, this also coincides with the release of the first iPhone in 2007). A final limitation was on the document type to exclude reviews.

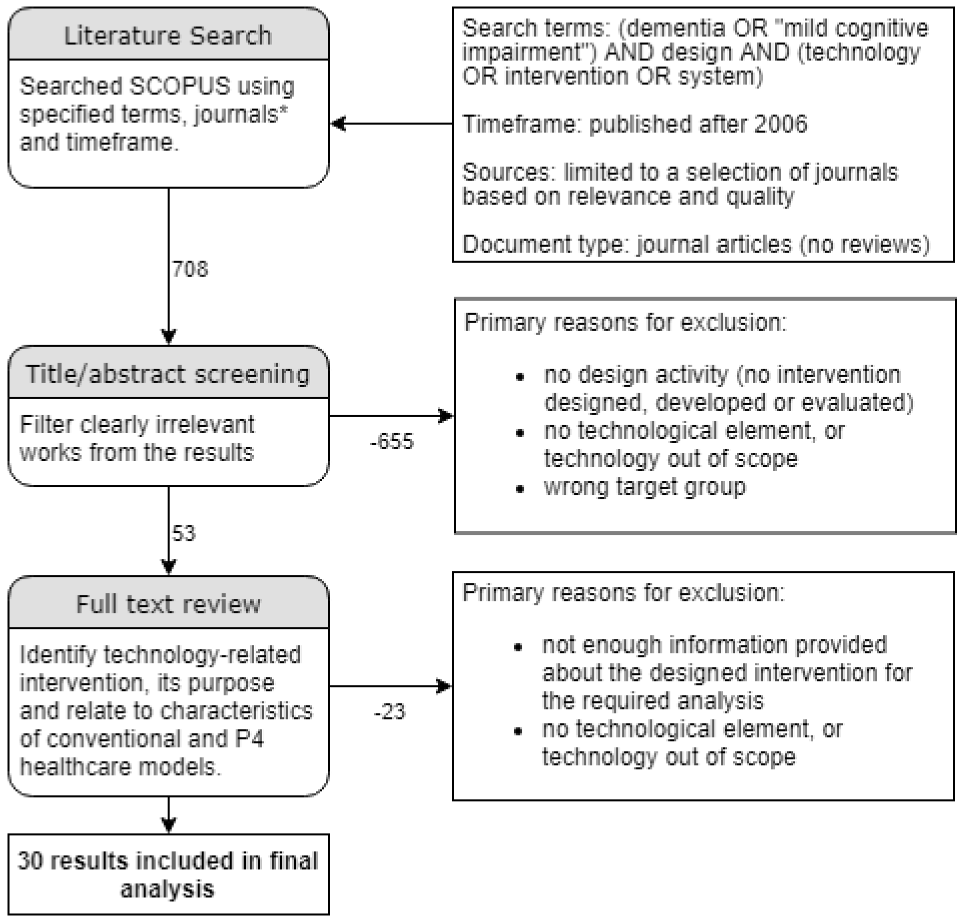

Figure 1. Overview of the systematic review process for searching and filtering literature

Selection process

The literature search yielded over 700 results from which 30 articles were ultimately included in the analysis. In a first selection round, all titles and abstracts were screened to filter results that clearly showed no relevance. Prominent reasons for exclusion were a lack of design activity, lack of an appropriate technological element, or wrong target group. A lack of design activity occurred where no intervention was designed, developed or evaluated, such as in observational studies, very basic research, perspective or commentary papers, and reviews. Interventions lacking an appropriate technological element typically included drugs, diet, physical activity, relaxation/stimulation activities, group therapy or other counselling approaches, or technology that was out of scope (e.g. an ordinary telephone). The screening process filtered most of the original search results, yielding 53 results for more detailed review.

In the second round, full-texts were reviewed to identify the specific intervention described in the article. A further 23 results were excluded in this process, mostly due to a lack of information provided about the intervention. This applied, for example, to articles describing very early design phases, such as a needs-gathering exercise, where the artefact to be designed was still largely abstract. Several exclusions were also due to the technological element being out of scope where this was only apparent from the full text.

Final review and analysis

A total of 30 articles met the criteria for inclusion in the final review and analysis. The goal of the analysis was to map healthcare design examples described in the articles to a set of characteristics of conventional and of P4 healthcare. For conventional healthcare, these were *reactive*, *episodic/discrete*, *generic* and *centralised*, and for P4 healthcare, these were each of the “P’s” (*preventative*, *predictive*, *personalised* and *participatory*) as well as *decentralised*. We considered decentralisation an important dimension of our analysis as we believe it to be orthogonal to the four P’s (each of the P’s not being intrinsically associated with a decentralised approach to care) yet critical to the future of healthcare. Our general view therefore extends that of the P4 framework, to one that also addresses the challenges of global health or those specific to acute care (Patou & Maier, 2017).

An overview of the characteristics is provided in Table 1. For each article, an intervention was identified along with its primary purpose. The article text was then analysed to find evidence supporting each of the characteristics in Table 1. Although certain characteristics from each of the healthcare models oppose one another directly (e.g. reactive vs preventative, and generic vs personalised), evidence supporting two opposing characteristics was documented for both where applicable. The results were used to populate a table relating each work to the set of characteristics (see Appendix B), and are described in the following section.

Table 1. Summary of characteristics of conventional and P4 healthcare used to review literature

Healthcare delivery	Characteristic	Description
Conventional	Reactive	Care/treatment is provided in reaction to an evident, existing condition (chronic or acute) to reduce its impact.
	Episodic (or discrete)	Patient interactions demanded by the intervention occur at sparse, discretely spaced intervals or episodes (e.g. spot measurements of physiological parameters such as blood pressure for hypertension at the doctor’s office, or pre-scheduled clinical assessments of cognitive impairment several months apart).
	Generic	The intervention is applied in the same way for all patients.
	Central	Patients interact with the intervention at a central location such as a hospital or other clinical setting.
P4 medicine	Predictive	The intervention is able to predict the disease onset/trajectory, the development of symptoms or their progression.
	Preventative	The onset or progression of a disease is prevented before its impact would otherwise become evident.
	Personalised	Treatment is tailored to the care recipient’s individual health/disease profile, lifestyle, behaviour and individual needs.
	Participatory	The care recipient plays an active role in making decisions about, planning and implementing their treatment/intervention in collaboration with healthcare professionals.
	Decentralised	The intervention supports a distributed care model by enabling interaction with the system in the user’s home/community environment.

Results

The review yielded results for 30 articles showing which characteristics apply to the healthcare interventions they present. Appendix B presents these results in full, providing the intervention, its purpose and a description of how it fulfils any applicable characteristics of conventional or P4 healthcare. An abridged version is provided in Table 2, indicating only which characteristics are fulfilled by each article but without supportive details.

Table 2. Abridged results relating articles to characteristics of conventional and P4 healthcare. Results are listed in descending, chronological order. Abbreviations: R = Reactive, E = episodic, G = generic, C = central, Pd = Predictive, Pv = preventative, Ps = personalised, Pt = participatory, D = decentralised.

#	Article	R	E	G	C	Pd	Pv	Ps	Pt	D
1	(Burton & O'Connell, 2018)						■	■	■	■
2	(Lindauer et al., 2017)	■	■	■						■
3	(Duggleby et al., 2017)			■				■		■
4	(Elfrink, Zuidema, Kunz, & Westerhof, 2017)							■	■	■
5	(Bahar-Fuchs et al., 2017)						■	■	■	■
6	(Lazarou et al., 2016)							■	■	■
7	(Jekel, Damian, Storf, Hausner, & Frölich, 2016)		■	■						■
8	(van de Weijer et al., 2016)						■	■		■
9	(Mirelman et al., 2016)						■	■	■	■
10	(van Knippenberg, de Vugt, Ponds, Myin-Germeys, & Verhey, 2016)	■		■				■	■	■
11	(Gaugler, Reese, & Tanler, 2016)		■					■	■	■
12	(Matthews et al., 2015)	■		■					■	■
13	(Tak, Zhang, Patel, & Hong, 2015)				■			■	■	
14	(Moreno, Elena Hernando, & Gomez, 2015)	■						■	■	■
15	(Baker, Huxley, Dennis, Islam, & Russell, 2015)			■					■	■
16	(Schaller et al., 2015)	■	■					■	■	■
17	(Cristancho-Lacroix et al., 2015)			■						■
18	(Boman, Lundberg, Starkhammar, & Nygård, 2014)	■		■			■			■
19	(Grindrod et al., 2014)		■		■		■	■	■	
20	(McKechnie, Barker, & Stott, 2014)		■	■					■	■
21	(Aloulou et al., 2013)	■			■			■		
22	(Blom, Bosmans, Cuijpers, Zarit, & Pot, 2013)		■	■			■		■	■
23	(García Vázquez, Moreno Martínez, Valero Duboy, & Gómez Oliva, 2012)							■		■
24	(F. J. M. M. Meiland et al., 2012)			■				■		■
25	(van Hoof, Kort, Rutten, & Duijnstee, 2011)	■					■	■		■
26	(Van Der Marck, Overeem, Klok, Bloem, & Munneke, 2011)	■		■						■
27	(Van Der Roest, Meiland, Jonker, & Droes, 2010)			■				■		■
28	(Hilbe, Schulc, Linder, & Them, 2010)			■	■		■			
29	(Mihailidis, Boger, Craig, & Hoey, 2008)							■		■
30	(Shoval et al., 2008)			■						■

Results of the analysis indicate that no single work achieves all characteristics of P4 healthcare, and that characteristics of conventional care apply sporadically, though diminishing in recent years. Not all elements of the P4 framework are progressing in unison: predictive care remains completely absent from the work reviewed, participatory care has emerged mainly in the last 2 years, while preventative and personalised care are more widespread. Nearly all works conform to a decentralised model, also reflected in sparsity of works characterised as "central" from conventional healthcare.

Discussion

The results of the literature review paint a picture of progression towards P4 healthcare from traditional healthcare models. We can see that, besides centralisation, characteristics associated with conventional healthcare permeate through the last decade and are scattered loosely across the results, diminishing over the last 2-3 years. Conversely, the results indicate that P4 healthcare is by no means established. In this section we comment on the status for each of the four P's, describing some of the shortcomings and obstacles, thereby providing a starting point from which to build recommendations for input from engineering design to help overcome these.

It is evident from the results that *predictive* is the characteristic lagging furthest behind, since it was entirely absent from the work reviewed. Prediction is arguably one of the foundational building blocks of P4 healthcare, often an enabler of the other three P's. Building predictive models for diagnosis, prognosis or therapy efficacy is generally difficult, particularly for syndromes such as dementia where both complex multigenic influences and numerous environmental and behavioural factors are at play. Yet prediction is becoming more achievable thanks to the increasing affordability, portability, pervasiveness and connectedness of multimodal data acquisition modalities (Andreu-Perez, Poon, Merrifield, Wong, & Yang, 2015; Topol, 2014). The collection and analysis of quality data remains a challenge, especially under a decentralised healthcare model in which data is generated "in the wild" without the controlled protocol that can be imposed under clinical supervision, and given the strict regulatory framework for processing personal data.

Several of the articles reviewed do describe the collection of data with potential predictive power, such as cognitive impairment evaluation scores (Lindauer et al., 2017), performance in cognitive training exercises or functional tasks (Bahar-Fuchs et al., 2017; Jekel et al., 2016; van de Weijer et al., 2016), and behaviour (e.g. sleep and physical activity patterns)(Lazarou et al., 2016). Even given successful data acquisition, substantial processing and analysis is needed to yield predictive insights. Combining multimodal data sources, developing machine-learning algorithms etc. depends on leveraging the latest developments from the prolific fields of data science and artificial intelligence (AI) (Andreu-Perez et al., 2015). Similar data-related challenges penetrate the rest of the P4 framework: personalisation depends directly on information pertaining to the individual (e.g. their symptoms, disease trajectory, wellbeing, behaviour and needs); and the availability of data empowers patients to self-manage their health and can facilitate collaboration with healthcare professionals for participatory care. As opportunities grow for users to generate data, how do we then harvest this to enhance care? Engineering design frameworks that support the design of P4 healthcare systems and services will need to address such questions and embrace the data-centrality of future healthcare.

Unlike predictive care, examples of preventative care are present among the results, though only sparsely. It is somewhat surprising to see prevention without prediction, since the prior depends (to some degree) on the latter: knowledge about a likely future occurrence helps us to prevent it. Without this information, preventative care manifests as a more generalised than targeted approach. This can be an implicit form of prevention, such as the use of cognitive/motor training exercises as a preventative measure against disease progression or falls (Mirelman et al., 2016; van de Weijer et al., 2016). In other cases prevention is achieved by casting the widest possible net, such as preventing wandering by detecting every single door-exit and confirming intent with the patient each time (van Hoof, Kort, Rutten, & Duijnstee, 2011b), or by detecting and responding to every bed-exit to prevent falls (Hilbe et al., 2010). Establishing predictive care (as well as personalisation) will in turn introduce the more detailed information regarding predicted disease trajectories, treatment response or individual risk profiles that is necessary to design smarter, targeted prevention strategies. While highly advantageous, predicting the occurrence of something only brings us so much closer to preventing it: knowledge (prediction) needs to be translated into action (prevention) through the designed intervention. This non-trivial task calls for a deep understanding of human behaviour, particularly motivation and engagement, to guide the design of interventions able to incite preventative action among patients (or healthy citizens). This is particularly relevant for the many chronic diseases that can be anticipated and prevented, and which are influenced by behaviour and lifestyle. Since the initial development and further progression of chronic diseases are generally influenced by behaviour and lifestyle, preventive healthcare strategies should be heavily founded on cognitive and behavioural theories, in particular those related to motivation, ownership, and engagement. Not only could this enhance prevention, but also it aligns with the concept of participatory care.

Personalised care is more abundant in the literature than preventative care, and in some cases, more data-driven. Other cases follow a similar trend described for preventative care in which the absence of data-derived inputs leads to more generalised, uninformed personalisation. This can be the partial personalisation achieved by customisation of an intervention with user input. Examples include a web portal offering caregiver support that is mostly generic, but with sections in which users can upload background information and patient-specific characteristics (Duggleby et al., 2017); or an online "life story book" for users (people with dementia and their caregivers) to complete with personal files and anecdotes (Elfrink et al., 2017). Another generalised form of personalisation is the design of interventions offering a wide range of functionality to be turned on/off or adjusted by the user to fit their individual needs. This is the case for the CogKnow Day Navigator assistive device for which users select from features such as calendar, reminders, activity assistance (F. J. M. Meiland et al., 2012); and a home safety system offering adjustable features and security levels (van Hoof et al., 2011). Healthcare should ideally be personalised both during the inception of a care strategy to best fit the individual care recipient's health profile, lifestyle and needs, and afterwards to adapt to changes in these. Some works limit personalisation to the initialisation of an intervention, e.g. based on the definition of personal goals (Burton & O'Connell, 2018), or user-input regarding demographic, illness-related, functional or psychosocial characteristics (Tak et al., 2015). In an example describing assisted living using a home sensor network, the intervention is tailored to user needs at start up and then adjusted based on new information obtained through behavioural monitoring (Lazarou et al., 2016). Several more results describe similar approaches to personalisation whereby an intervention continuously adapts to changes in users' needs based on auto-generated data streams. Examples include adjusting the difficulty level of training exercises based on user performance (Bahar-Fuchs et al., 2017; van de Weijer et al., 2016), or adapting computer-based guidance for activities of daily living based on user performance, responsiveness and feedback (Mihailidis et al., 2008). Adaptive care that responds to changes in users' needs need not be automated, as in the case of caregiver support adapted based on face-to-face user-feedback sessions (van Knippenberg et al., 2016), however leveraging digital data for personalisation offers a level of scalability that is unobtainable using conventional methods, making this a promising direction for overburdened healthcare systems. Herein lies a potential shortcoming of current engineering design methods: while offering ample support for gathering, understanding and responding to users' needs, this tends to be based on data obtained through interviews, focus groups, surveys etc. New approaches are needed for scalable intervention design tailored to users' individual needs based on data streams describing users' health, lifestyle and behaviour, and how these change over time (Thorpe, Forchhammer, & Maier, 2016; Thorpe, Hysse Forchhammer, & Maier, 2017). Again, this highlights the importance of both data-centrality and of cognitive and behavioural theories discussed in the previous sections as considerations for engineering design frameworks to support P4 healthcare.

Participatory care enters the scene relatively recently (2013) in our results, but with a high concentration of works thereafter. The extent to which participatory care is achieved varies, opening critical questions about the interpretation and implementation of participative care in practice. Collaboration is at the core of participatory care, which relies on patient engagement in the planning and execution of strategies to prevent or manage disease or otherwise improve their health and wellbeing. In the case of dementia care, the "patient" in this collaboration extends to include the primary caregiver of the patient (typically a spouse or other close relative). In its current format (based on the results of the literature review), participation is mostly limited to a subset of (or single) decisions and activities comprising the full care approach. One such version of participation is close collaboration between healthcare professional and caregiver in the delivery of care to the person with dementia (Gaugler et al., 2016; Matthews et al., 2015; Schaller et al., 2015). Another is where data concerning the user's cognition, functional capacity, behaviour or other health-related information that is generated is also shared with the user so that they can track their own performance and progress (Bahar-Fuchs et al., 2017; Mirelman et al., 2016). Allowing the patient to define how and when they employ an intervention instead of relying solely on instruction from the healthcare professional prescribing its' use also constitutes a form of participative care, and is evident in the example of a computer-based cognitive stimulation intervention (Tak et al., 2015). A single work demonstrated all aforementioned aspects of participatory care, wherein the user participates in defining the care strategy and intervention goals, can access their own data to follow their progress, and in which communication with a healthcare professional is encouraged and facilitated by a messaging system incorporated into the system (Lazarou et al., 2016). Design- and systems-thinking and engineering design methodologies can help achieve better outcomes if, as a starting point, the fundamental requirements and contextual factors motivating the participative approach are taken into account. It is important to acknowledge that participation in the context of design has a distinctly different meaning from that of participatory care. A wealth of engineering design knowledge exists to support the retrieval of design input from users (e.g. from co-design, inclusive design or participatory design methods), however participatory care is not about gathering input from users to inform design, it is about designing user empowerment into the system, addressing *who* makes care decisions and *how*, based on *what* information flow.

We now shift our focus away from the four P's to *decentralisation*, the additional and final characteristic considered regarding future healthcare systems. Decentralisation abounds. It appears from the results that so far, technology's ability to bring care out of the clinic and into people's homes has been widely exploited, while incorporation of other offerings of technological advancement into the design of healthcare systems is only gradually catching up. Decentralisation *without* the simultaneous development of P4 healthcare can result in the cleavage of two entities: in one, the patient in their home environment using technology, and in the other the healthcare professional in the clinical environment devising care strategies (including the prescription of technological support). This scenario is depicted in **Figure 2A**. The P4 healthcare framework not only connects these entities, but also depends upon their connection for its advancement. Prediction requires information generated in a decentralised way. The transfer of this and other knowledge between healthcare providers and recipients (patients) enables targeted prevention and personalisation of care strategies. Formulation and implementation of these strategies based on input from both entities relies on a participative care model, which serves to link all elements in the system. This desired scenario is depicted in **Figure 2B**.

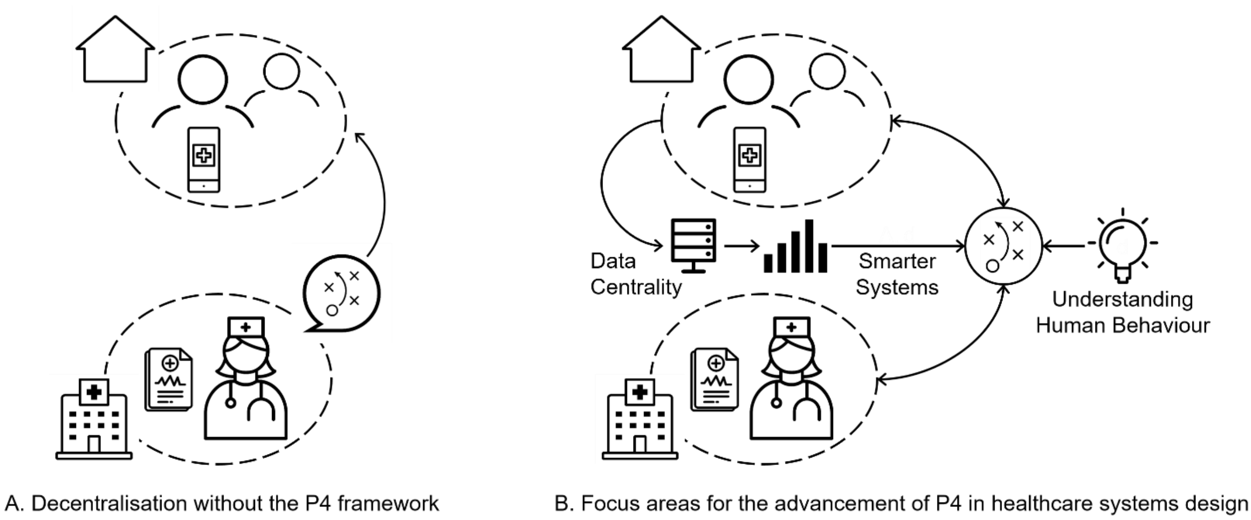

Figure 2. Current and desired healthcare system models: A) A decentralised healthcare model without the P4 framework results in two separate entities (patient at home using healthcare technology, healthcare provider in a clinical setting with patient records), with care strategies devised primarily by healthcare professionals. B) Proactive and collaborative healthcare model showing three focus areas (data centrality, smarter systems, understanding human behaviour) to advance the P4 framework.

We view support from engineering systems and design fields as imperative for realising the P4 vision through healthcare system design. Based on insight gained from the review of the literature and findings discussed in this section, we recommend the following key focus areas:

Data-centrality: systematic collection, aggregation and analysis of data from multiple sources is fundamental to P4 healthcare. Engineering design methods and theories aligned to the central role of data in healthcare systems are required to propel progress.

Designing smarter systems: once data-related stumbling blocks are overcome, new knowledge and insights will become available regarding predicted trajectories/events and patient characteristics and needs. We need design approaches capable of applying this knowledge in the design of smarter interventions for more targeted prevention, comprehensive personalisation, and that adapt to change.

Understanding human behaviour: For care interventions to incite the desired action in care recipients for disease prevention and management, data-derived knowledge alone is insufficient. Engineering design frameworks should be heavily founded on cognitive and behavioural theories to support motivation and engagement, and foster collaboration.

Conclusion

This paper looks into the transformation of our healthcare systems towards the proactive, decentralised care delivery of P4 medicine, highlighting the need for holistic engineering design frameworks. We have examined the status of progress from conventional to P4 healthcare, pinpointing key challenges and proposing how engineering design and systems thinking might address these. We present a systematic review of literature including the most recent decade of healthcare technology design, using dementia care as a case example. A review of 708 articles yielded 30 relevant works which were mapped to characteristics of conventional (reactive, episodic, generic, central) and P4 healthcare (predictive, preventative, personalised, participatory, as well as decentralised). Our results show that while decentralisation is well established, there is only limited preventative, personalised or participatory care, and an absence of predictive care approaches in the reviewed literature. The availability, acquisition and analysis of data could be inhibiting factors, particularly for prediction and personalisation, which are necessary for targeted prevention. Besides adequate data infrastructures, participatory care demands a considered approach to patient motivation, engagement and empowerment. We therefore recognise three key focus areas for the development of holistic frameworks to support the design of P4 healthcare systems: data-centrality, designing smarter systems, and understanding human behaviour.

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References

Aloulou, H., Mokhtari, M., Tiberghien, T., Biswas, J., Phua, C., Kenneth Lin, J. H., & Yap, P. (2013). Deployment of assistive living technology in a nursing home environment: methods and lessons learned. BMC Medical Informatics and Decision Making, 13, 42.

Andreu-Perez, J., Poon, C. C. Y., Merrifield, R. D., Wong, S. T. C., & Yang, G.-Z. (2015). Big Data for Health. *IEEE Journal of Biomedical and Health Informatics*, *19*(4), 1193–1208.

Bahar-Fuchs, A., Webb, S., Bartsch, L., Clare, L., Rebok, G., Cherbuin, N., & Anstey, K. J. (2017). Tailored and Adaptive Computerized Cognitive Training in Older Adults at Risk for Dementia: A Randomized Controlled Trial. *Journal of Alzheimer's Disease*, *60*(3), 889–911.

Baker, C., Huxley, P., Dennis, M., Islam, S., & Russell, I. (2015). Alleviating staff stress in care homes for people with dementia: Protocol for stepped-wedge cluster randomised trial to evaluate a web-based Mindfulness- Stress Reduction course. *BMC Psychiatry*, *15*(1), 1–9.

Bardram, J. E., & Frost, M. (2016). The Personal Health Technology Design Space. *IEEE Pervasive Computing*, *15*(2), 70–78.

Blom, M. M., Bosmans, J. E., Cuijpers, P., Zarit, S. H., & Pot, A. M. (2013). Effectiveness and cost-effectiveness of an internet intervention for family caregivers of people with dementia : design of a randomized controlled trial. *BMC Psychiatry*, *13*, 1–7.

Boman, I.-L. L., Lundberg, S., Starkhammar, S., & Nygård, L. (2014). Exploring the usability of a videophone mock-up for persons with dementia and their significant others. *BMC Geriatrics*, *14*(1).

Burton, R. L., & O'Connell, M. E. (2018). Telehealth Rehabilitation for Cognitive Impairment: Randomized Controlled Feasibility Trial. *JMIR Research Protocols*, *7*(2), e43.

Christensen, J., Hasman, A., & Hunter, L. (2010). *Engineering the System of Healthcare Delivery*. (W. B. Rouse & D. A. Cortese, Eds.). IOS Press BV.

Craig, C., & Chamberlain, P. (2017). Behaviours: Design and behaviour change in health. In E. Tsekleves & R. Cooper (Eds.), *Design for health* (pp. 191–203). Abingdon: Routledge.

Cristancho-Lacroix, V., Wrobel, J., Cantegreil-Kallen, I., Dub, T., Rouquette, A., Rigaud, A., & Publique -Hôpitaux de Paris, A. (2015). A Web-Based Psychoeducational Program for Informal Caregivers of Patients With Alzheimer's Disease: A Pilot Randomized Controlled Trial. *Journal of Medical Internet Research*, *1717*(5), 117.

Cutler, D. M., Rosen, A. B., & Vijan, S. (2006). The Value of Medical Spending in the United States, 1960–2000. *New England Journal of Medicine*, *355*(9), 920–927.

Doss, H. (2014). Design Thinking In Healthcare: One Step At A Time.

Duggleby, W., Ploeg, J., McAiney, C., Fisher, K., Swindle, J., Chambers, T., … Pollard, L. (2017). Study protocol: Pragmatic randomized control trial of an internet-based intervention (My tools 4 care) for family carers. *BMC Geriatrics*, *17*(1), 1–9.

Elfrink, T. R., Zuidema, S. U., Kunz, M., & Westerhof, G. J. (2017). The effectiveness of creating an online life story book on persons with early dementia and their informal caregivers: a protocol of a randomized controlled trial. *BMC Geriatrics*, *17*(1), 1–11.

Flores, M., Glusman, G., Brogaard, K., Price, N. D., & Hood, L. (2013). P4 medicine: how systems medicine will transform the healthcare sector and society. *Personalized Medicine*, *10*(6), 565–576.

García Vázquez, C., Moreno Martínez, E., Valero Duboy, M. Á., & Gómez Oliva, A. (2012). Distributed system for cognitive stimulation over interactive TV. *IEEE Transactions on Information Technology in Biomedicine*, *16*(6), 1115–1121.

Gaugler, J. E., Reese, M., & Tanler, R. (2016). Care to plan: An online tool that offers tailored support to dementia caregivers. *Gerontologist*, *56*(6), 1161–1174.

Grindrod, K. A., Gates, A., Dolovich, L., Slavcev, R., Drimmie, R., Aghaei, B., … Leat, S. J. (2014). ClereMed: Lessons learned from a pilot study of a mobile screening tool to identify and support adults who have difficulty with medication labels. *Journal of Medical Internet Research*, *16*(8), e35.

Hendriks, N., Slegers, K., & Duysburgh, P. (2015). Codesign with people living with cognitive or sensory impairments: a case for method stories and uniqueness. *CoDesign*, *11*(1), 70–82.

Hilbe, J., Schulc, E., Linder, B., & Them, C. (2010). Development and alarm threshold evaluation of a side rail integrated sensor technology for the prevention of falls. *International Journal of Medical Informatics*, *79*(3), 173–180.

Hood, L. (2008). A systems approach to medicine will transform healthcare. *Physical Biology: From Atoms To Medicine*.

Hood, L., & Auffray, C. (2013). Participatory medicine: A driving force for revolutionizing healthcare. *Genome Medicine*, *5*(12), 110.

Hood, L., Balling, R., & Auffray, C. (2012). Revolutionizing medicine in the 21st century through systems approaches. *Biotechnology Journal*, *7*(8), 992–1001.

Jekel, K., Damian, M., Storf, H., Hausner, L., & Frölich, L. (2016). Development of a Proxy-Free Objective Assessment Tool of Instrumental Activities of Daily Living in Mild Cognitive Impairment Using Smart Home Technologies. *Journal of Alzheimer's Disease*, *52*(2), 509–517.

John Clarkson, P., & Coleman, R. (2015). History of Inclusive Design in the UK. *Applied Ergonomics*, *46 Pt B*, 235–247.

Kim, S. H., Myers, C. G., & Allen, L. (2017). Health Care Providers Can Use Design Thinking to Improve Patient Experiences.

Kivimäki, M., & Batty, G. D. (2016). Evidence-based prevention and treatment of dementia. *The Lancet Neurology*, *15*(10), 1005.

Komashie, A., & Clarkson, P. J. (2018). DESIGNING MENTAL HEALTH DELIVERY SYSTEMS : DESCRIBING THE RELATIONSHIP BETWEEN SYSTEM COMPONENTS. *INTERNATIONAL DESIGN CONFERENCE - DESIGN 2018*, 2669–2680.

Ku, B., & Rosen, P. (2016). Making Design Thinking a Part of Medical Education.

Lamé, G. (2018). POSITION PAPER : ON DESIGN RESEARCH ENGAGING WITH HEALTHCARE SYSTEMS. *INTERNATIONAL DESIGN CONFERENCE - DESIGN 2018*, 2681–2692.

Lazarou, I., Karakostas, A., Stavropoulos, T. G., Tsompanidis, T., Meditskos, G., Kompatsiaris, I., & Tsolaki, M. (2016). A Novel and Intelligent Home Monitoring System for Care Support of Elders with Cognitive Impairment. *Journal of Alzheimer's Disease*, *54*(4), 1561–1591.

Lindauer, A., Seelye, A., Lyons, B., Dodge, H. H., Mattek, N., Mincks, K., … Erten-Lyons, D. (2017). Dementia Care Comes Home: Patient and Caregiver Assessment via Telemedicine. *Gerontologist*, *57*(5), e85–e93.

Matthews, J. T., Lingler, J. H., Campbell, G. B., Hunsaker, A. E., Hu, L., Pires, B. R., … Schulz, R. (2015). Usability of a Wearable Camera System for Dementia Family Caregivers. *Journal of Healthcare Engineering*, *6*(2), 213–238.

McKechnie, V., Barker, C., & Stott, J. (2014). The effectiveness of an internet support forum for carers of people with dementia: A pre-post cohort study. *Journal of Medical Internet Research*, *16*(2), 1–14.

Meiland, F. J. M., Bouman, A. I. E., Sävenstedt, S., Bentvelzen, S., Davies, R. J., Mulvenna, M. D., … Dröes, R. M. (2012). Usability of a new electronic assistive device for community-dwelling persons with mild dementia. *Aging and Mental Health*, *16*(5), 584–591.

Meiland, F. J. M. M., Bouman, A. I. E. E., Sävenstedt, S., Bentvelzen, S., Davies, R. J., Mulvenna, M. D., … Dröes, R.-M. M. (2012). Usability of a new electronic assistive device for community-dwelling persons with mild dementia. *Aging and Mental Health*, *16*(5), 584–591.

Mihailidis, A., Boger, J. N., Craig, T., & Hoey, J. (2008). The COACH prompting system to assist older adults with dementia through handwashing: an efficacy study. *BMC Geriatrics*, *8*, 28.

Mirelman, A., Rochester, L., Maidan, I., Del Din, S., Alcock, L., & Nieuwhof, F. (2016). Addition of a non-immersive virtual reality component to treadmill training to reduce fall risk in older adults (V-TIME): A randomized control trial. *Lancet*, *388*.

Møller, T., & Kettley, S. (2017). Wearable health technology design: A humanist accessory approach. *International Journal of Design*, *11*(3), 35–49.

Moreno, P. A., Elena Hernando, M., & Gomez, E. J. (2015). Design and technical evaluation of an enhanced location-awareness service enabler for spatial disorientation management of elderly with mild cognitive impairment. *IEEE Journal of Biomedical and Health Informatics*, *19*(1), 37–43.

Mullaney, T., Pettersson, H., Nyholm, T., & Stolterman, E. (2012). Thinking beyond the Cure: A Case for Human-Centered Design in Cancer Care | International Journal of Design. Retrieved April 29, 2015, from http://index.ijdesign.org/?p=2189

Norton, S., Matthews, F. E., Barnes, D. E., Yaffe, K., & Brayne, C. (2014). Potential for primary prevention of Alzheimer's disease: An analysis of population-based data. *The Lancet Neurology*, *13*(8), 788–794.

Patou, F., & Maier, A. (2017). Engineering Value-Effective Healthcare Solutions: A Systems Design Perspective. In *Proceedings of the 21st International Conference on Engineering Design (ICED17), Vol. 3: Product, Services and Systems Design* (pp. 31–41). Design Society.

Price, N. D., Foltz, G., Madan, A., Hood, L., & Tian, Q. (2008). Systems biology and cancer stem cells. *Journal of Cellular and Molecular Medicine*, *12*(1), 97–110.

Prince, M., Wimo, A., Guerchet, M., Gemma-Claire, A., Wu, Y.-T., & Prina, M. (2015). World Alzheimer Report 2015: The Global Impact of Dementia - An analysis of prevalence, incidence, cost and trends. *Alzheimer's Disease International*, 84.

Rouse, W. B., & Serban, N. (2014). *Understanding and managing the complexity of healthcare*. *Understanding and Managing the Complexity of Healthcare*.

Royal Academy of Engineering. (2017). *Engineering better care a systems approach to health and care design and continuous improvement*.

Sabia, S., Dugravot, A., Dartigues, J.-F., Abell, J., Elbaz, A., Kivimäki, M., & Singh-Manoux, A. (2017). Physical activity, cognitive decline, and risk of dementia: 28 year follow-up of Whitehall II cohort study. *Bmj*, *2709*(June), j2709.

Sagner, M., McNeil, A., Puska, P., Auffray, C., Price, N. D., Hood, L., … Arena, R. (2017). The P4 Health Spectrum – A Predictive, Preventive, Personalized and Participatory Continuum for Promoting Healthspan. *Progress in Cardiovascular Diseases*, *59*(5), 506–521.

Schaller, S., Marinova-Schmidt, V., Gobin, J., Criegee-Rieck, M., Griebel, L., Engel, S., … Kolominsky-Rabas, P. L. (2015). Tailored e-Health services for the dementia care setting: A pilot study of "eHealthMonitor." *BMC Medical Informatics and Decision Making*, *15*(1), 1–9.

Shoval, N., Auslander, G. K., Freytag, T., Landau, R., Oswald, F., Seidl, U., … Heinik, J. (2008). The use of advanced tracking technologies for the analysis of mobility in Alzheimer's disease and related cognitive diseases. *BMC Geriatrics*, *8*, 7.

Spillman, B. C., & Lubitz, J. (2000). The Effect of Longevity on Spending for Acute and Long-Term Care. *New England Journal of Medicine*, *342*(19), 1409–1415.

Swan, M. (2012). Health 2050: The Realization of Personalized Medicine through Crowdsourcing, the Quantified Self, and the Participatory Biocitizen. *Journal of Personalized Medicine*, *2*(4), 93–118.

Tak, S. H., Zhang, H., Patel, H., & Hong, S. H. (2015). Computer activities for persons with dementia. *Gerontologist*, *55*(December), S140–S149.

Thorpe, J. R., Forchhammer, B. H., & Maier, A. (2016). Needs Elicitation for Novel Pervasive Healthcare Technology. *14th International Design Conference - Design 2016*. Design Society.

Thorpe, J. R., Hysse Forchhammer, B., & Maier, A. (2017). Sensing behaviour in healthcare design. In *Proceedings of the 21st International Conference on Engineering Design (ICED17), Vol. 3: Product, Services and Systems Design* (pp. 171–181). Design Society.

Tobiasson, H., Sundblad, Y., Walldius, Å., & Hedman, A. (2015). Designing for Active Life: Moving and Being Moved Together with Dementia Patients. *International Journal of Design*, *9*(3), 47–62.

Topol, E. J. (2014). Individualized medicine from prewomb to tomb. *Cell*, *157*(1), 241–253.

van de Weijer, S. C. F., Duits, A. A., Bloem, B. R., Kessels, R. P., Jansen, J. F. A., Köhler, S., … Kuijf, M. L. (2016). The Parkin'Play study: protocol of a phase II randomized controlled trial to assess the effects of a health game on cognition in Parkinson's disease. *BMC Neurology*, *16*(1), 209.

Van Der Marck, M. A., Overeem, S., Klok, P. C. M., Bloem, B. R., & Munneke, M. (2011). Evaluation of the falls telephone: An automated system for enduring assessment of falls. *Journal of the American Geriatrics Society*, *59*(2), 340–344.

Van Der Roest, H. G., Meiland, F. J. M., Jonker, C., & Dr??es, R. M. (2010). User evaluation of the DEMentia-specific Digital Interactive Social Chart (DEM-DISC). A pilot study among informal carers on its impact, user friendliness and, usefulness. *Aging and Mental Health*, *14*(4), 461–470.

van Hoof, J., Kort, H. S. M., Rutten, P. G. S., & Duijnstee, M. S. H. (2011). Ageing-in-place with the use of ambient intelligence technology: Perspectives of older users. *International Journal of Medical Informatics*, *80*(5), 310–331.

van Knippenberg, R. J. M., de Vugt, M. E., Ponds, R. W., Myin-Germeys, I., & Verhey, F. R. J. (2016). Dealing with daily challenges in dementia (deal-id study): effectiveness of the experience sampling method intervention'Partner in Sight'for spousal caregivers of people with dementia: design of a randomized controlled trial. *BMC Psychiatry*, *16*(1), 136.

Westont, A. D., & Hood, L. (2004). Systems Biology, Proteomics, and the Future of Health Care: Toward Predictive, Preventative, and Personalized Medicine. *Journal of Proteome Research*, *3*(2), 179–196.

WHO. (2009). *Systems thinking for health systems strengthening* (Vol. 7).

[Article Appendix] A: Journals List

Engineering Design

International Journal of Design
Systems Engineering
Journal of Engineering and Technology Management
Design Studies
Design Science
Research in Engineering Design
Journal of Engineering Design
Journal of Mechanical Design

Biomedical and Technical:

IEEE journals: Transactions on Engineering Management, Journal of Biomedical and Health Informatics, Systems Journal, Transactions on Biomedical Engineering, Transactions on Systems, Man and Cybernetics, Transactions On Information Technology in Biomedicine
Advanced Engineering Informatics
International Journal of Medical Informatics
Journal of Medical Internet Research
Journal of Biomedical Informatics
British Medical Journal (BMJ)
PLOS ONE

Medical, clinical or gerontology:

BioMed Central (BMC) Journals
The Lancet
New England Journal of Medicine
Journal of the American Medical Association (JAMA)
The Journals of Gerontology
Age and aging
Aging and Mental Health
Alzheimer’s and Dementia
Archives of Gerontology and Geriatrics"
BMC Geriatrics
Dementia and Geriatric Cognitive Disorders
Geriatrics and Gerontology International
Gerontechnology
Gerontology

Journal of Aging and Health
Journal of Aging and Physical Activity
Journal of Alzheimer's Disease
Journal of Applied Gerontology
Journal of healthcare engineering
Journal of Healthcare Management
Journal of the American Geriatrics Society
The Gerontologist

[Article Appendix] B: Unabridged results of the literature review

#	Paper	Intervention	Purpose	Reactive	Episodic	Generic	Central	Predictive	Preventative	Personalised	Participatory	Decentralised
1	(Burton & O'Connell, 2018)	Telehealth solution using videoconferencing for goal-oriented cognitive rehabilitation among people with dementia	Widen access to care through remote delivery						Cognitive rehabilitation is used to help patients attain functional goals, thereby preventing functional decline.	Personalised goals are set for the cognitive rehabilitation intervention based on patients' individual needs and preferences	The patient works together with the healthcare professional in setting, monitoring and achieving their goals.	Videoconferencing enables patient-healthcare professional interactions to take place at home for remote cognitive rehabilitation
2	(Lindauer et al., 2017)	Telemedicine-based assessments (cognitive, behaviour and mood) using videoconferencing	Widen access to care for people with dementia by enabling assessment to take place at home	The focus is assessment and not consequent actions, however it is assumed that a clinician acts based on patients' assessment scores (for cognition, mood and behaviour) which describe current/past status.	The telemedicine assessments are used for spot measurement of patients' cognition, behaviour and mood (frequency not given, typically at intervals of several months).	A battery of tests (MoCA, CDR, GDS, ZBI, RMBPC, MMCGI-SF) are used that are standard for rating cognitive function, disease stage, depression and caregiver burden.						Assessments are completed at home using telecommunication technology
3	(Duggleby et al., 2017)	Online intervention for caregiver support that provides information relevant for their role as caregiver (e.g. expected transitions, available resources), and a means for storing and tracking health information about the care recipient.	Improve caregiver self-efficacy and quality of life			The online caregiver support tool comprises mostly generic information (read only).				Two sections (tabs) of the online caregiver support allow caregivers to enter personal background information, upload files or record patient-specific characteristics.		Intended for caregivers to use at home as a tool for support.
4	(Elfrink et al., 2017)	Online Life Story Book (OLSB) reminiscence intervention for people with dementia to document and review significant	Improve PwD quality of life by reducing neuropsychotic symptoms							The content of the life story book (online tool) is made up of text, photos, movies, sound/music	The lifestory book is intended as a tool for reminiscence therapy for collaborative use by PwD,	The storybook is web-based and thus intended for home use as a tool for reminiscence

#	Paper	Intervention	Purpose	Reactive	Episodic	Generic	Central	Predictive	Preventative	Personalised	Participatory	Decentralised
		memories from their lives using an online platform.								that is customised to reflect the user's personal history and interests.	their caregivers and a volunteer (representative of a healthcare professional).	therapy activities, which are to take place at home.
5	(Bahar-Fuchs et al., 2017)	An adaptive cognitive training programme (CogniFit) for people with mild cognitive impairment that provides domain-specific and global cognitive scores.	To reduce symptoms and slow disease progression for people with cognitive impairment by engaging them in cognitively stimulating activities.						The intervention uses cognitive stimulation to prevent disease progression among people with cognitive impairment.	The CogniFit tool tailors cognitive training tasks to individual profiles based on scores it calculates for the user. Task difficulty is continuously adapted according to the user's performance.	The user receives feedback on their cognitive training tasks (a score), which allows them to track their progress.	The CogniFit system described is intended for cognitive training in a home setting
6	(Lazarou et al., 2016)	Assisted living solution comprising a multi-sensor system that detects behaviour (sleep patterns, physical activity and activities of daily living) for targeted psychosocial interventions.	Improve care quality and enhance patient quality of life, cognitive function and functional performance.							At start up the intervention is tailored to individual patients' key problems. The care strategy is then adapted based on continuous behavioural monitoring.	The patient participates in defining intervention goals, can access their data to monitor their own behaviour, and communicate with the clinician via a messaging system.	The sensor system is located in the patient's home and communication between the clinician and patient/caregive r takes place via a messaging system.
7	(Jekel et al., 2016)	Smart home environment for assessment of IADL in MCI without requiring input from a caregiver.	Reliable and objective assessment method for evaluating activities of daily living (among people with mild cognitive impairment)		An episodic evaluation is described whereby participants complete set tasks as a smart-home based alternative to conventional assessments.	The sensor system and tasks are the same for all participants						Home based assessment replaces alternatives carried out in a clinical setting.
8	(van de Weijer et al., 2016)	Web-based cognitive health game targeting multiple cognitive domains (attention, working memory, episodic memory,	Improve cognition among Parkinson's disease patients						Cognitive training game aims to prevent cognitive decline among people with	Cognitive training game speed and difficulty are tailored to users' level and		Web-based cognitive health game designed for home use

#	Paper	Intervention	Purpose	Reactive	Episodic	Generic	Central	Predictive	Preventative	Personalised	Participatory	Decentralised
		psychomotor speed and executive function)							Parkinson's disease	weak areas based on performance and regular assessments.		
9	(Mirelman et al., 2016)	Fall prevention system comprising treadmill training with a VR component	Prevent falls in high-risk older adults by training both motor and cognitive function						The primary goal of the training system is to prevent falls	The training system is adaptive, progressing according to the user's individual performance.	Users receive visual and auditory feedback of their performance during and after training sessions.	The fall prevention system involves home-based training
10	(van Knippenberg et al., 2016)	"Partner-in-sight" experience sampling intervention using an electronic touchscreen device (PsyMate) to generate questions regarding mood (affect) and current context/activities. Face-to-face feedback on the results is provided to caregivers (users) every two weeks.	Support caregivers / reduce caregiver burden: to improve their feelings of competence and control and reduce psychological complaints.	The intervention provides caregivers with insights into past behaviours and experiences, so that they can respond (react) by adjusting their behaviour towards those that invoke positive experiences		The partner-in-sight intervention follows the same configuration for all users in terms of the questions asked, question and feedback schedule and equipment.				The course of action followed by caregivers to improve their life quality is based on feedback sessions with a coach, and is thus personalised according to their individual experiences.	The caregiver takes part in feedback sessions with a coach, intended to empower them to recognise and increase behaviours and contexts conducive to positive experiences.	The experience sampling intervention is used in all contexts of daily living.
11	(Gaugler et al., 2016)	Online tool for dementia caregivers ("Care to Plan") that generates tailored support recommendations	To support caregivers of people with dementia with planning the care process		The tool is used specifically at a point in time when support (for a person with dementia) is selected, guiding the decision up until a selection is made and not beyond.					The system provides tailored support recommendations for dementia caregivers based on input that they provide regarding their situation.	Counsellors review the tailored support recommendations generated by the online tool with caregivers, and the selection process is completed together.	The intervention comprises a web-based portal intended for use by dementia caregivers at home.
12	(Matthews et al., 2015)	Wearable camera for dementia caregivers to record care-recipient's behaviour and interpersonal dynamics of caregiving dyads.	The system aims to provide objective evidence of behavioural, physical, and emotional manifestations of dementia to facilitate clinical	The wearable camera captures evidence of already existing behavioural symptoms such that these can be responded to.		The wearable camera intervention follows the same design and use for all					Caregivers participate by capturing and discussing the data that is recorded (e.g. events exemplifying problematic behaviour or	The wearable camera system is used by a caregiver at home (and everywhere else they go).

#	Paper	Intervention	Purpose	Reactive	Episodic	Generic	Central	Predictive	Preventative	Personalised	Participatory	Decentralised
			discussion of care strategies								other symptoms) with a healthcare professional	
13	(Tak et al., 2015)	Computer activity programs involving email, internet search, computerised games, and slideshow modules to promote cognitive stimulation and positive emotion	To engage nursing home residents and improve their health outcomes in terms of affective, behavioural and cognitive characteristics				The study presented is implemented in a care home, and proposes a dedicated laboratory for computer activities.			The format, content and procedure for computer activity interventions are tailored to individual characteristics (demographic, illness-related, cognitive and physical functioning, psychosocial).	The user (person with dementia) decides for themselves how to engage in the intervention (e.g. which activities and for how long)	
14	(Moreno et al., 2015)	Location awareness service to support people with dementia when they are disoriented and to detect wandering behaviour (or hazardous situations) and send alerts to contacts.	Improve safety for people with dementia in the case of disorientation and wandering, thus encouraging more independent and active lifestyles.	The system responds to events such as a panic button being pressed, a user demonstrating wandering behaviour, or a hazardous situation.						The location awareness system is customised with the user's individual "hot spots" (secure places where the user goes) and contacts.	The person with dementia can indicate their own perceived safety. Setting up the system with the user's personal settings (e.g. safe areas) is a collaborative activity with the doctor and user's contacts.	The location awareness system is mobile and used anywhere during daily life.
15	(Baker et al., 2015)	Web-based mindfulness stress reduction course for staff in care homes for people with dementia	Improve the wellbeing of staff in care homes (reduce stress, absence and turnover rates), thereby improving the quality of care they provide to residents.			The mindfulness course is identical for all users (in terms of the videos, exercises and assignments).					Users follow their progress through the mindfulness course using online tools.	The mindfulness course is web-based for use at home (or other remote setting).
16	(Schaller et al., 2015)	eHM Dementia Portal for communication between caregivers and medical professionals. Caregivers provide information about the	To support caregivers of people with dementia by providing them with a decision aid, thereby empowering them	Caregivers provide information about symptoms/wellbeing of the PwD, to which medical	The service supports caregivers in making care decisions based on symptoms, thereby following a					The web portal is intended to enable more personalised support from medical professionals for people with	While the approach does not directly involve patients, it supports significant involvement of informal	The intervention comprises a web portal for home-based use and remote communication with healthcare professionals

#	Paper	Intervention	Purpose	Reactive	Episodic	Generic	Central	Predictive	Preventative	Personalised	Participatory	Decentralised
		PwD's symptoms, medication, well-being and other needs. Medical professionals respond with personalised support.	to make informed care decisions	professionals can respond (react) with a recommended course of action.	conventional format of spaced, episodic care.					dementia based on input about symptoms/wellbeing provided by their caregivers	caregivers in making care decisions	
17	(Cristancho-Lacroix et al., 2015)	Diapason: a web-based, fully automated psychoeducational program for caregivers of people with dementia, targeting caregivers' beliefs about dementia and caregiving, skills in managing daily life, and social support.	To improve accessibility of support/resources to caregivers who may feel overburdened or isolated			Then programme content is generic, there is no customisation or capability to enter personalised information.						The caregiver support programme is web-based for home use.
18	(Boman et al., 2014)	Video phone for people with dementia to communicate with their social network and elicit help when needed	Improve social engagement and safety for people with dementia by providing a means of communication	One aim of the videophone is for users to get help when needed, which can be understood as reacting to an emergency (rather than preventing it).		The videophone is identical for all users (used in the same way for the same purposes).			The videophone is intended to prevent social isolation.			The videophone is designed for home use without assistance
19	(Grindrod et al., 2014)	An iPad app that screens patients to determine their ability to read and follow medication instructions, consequently providing recommendations to pharmacists for improved accessibility when necessary.	Improve accessibility of medication information, thereby increasing medication adherence.		The app is used only for patient-pharmacist interactions when medication is supplied.		Intended for use at a pharmacy for collection of medication		The app is intended to prevent incorrect medication use.	A screening step informs the pharmacist about how medication information should be personalised for the individual patient, primarily by adjusting font-size.	Determining the patient's ability to read medication information is a collaborative exercise involving the patient, pharmacist and support tool.	
20	(McKechnie et al., 2014)	"Talking Point" is an online support and discussion forum for carers of people with dementia	To improve quality of life for caregivers of people with dementia in terms of their physical and mental burden		The online support forum is intended for on-going but ad-hoc use according to the	The forum follows a generic design (content, appearance, functionality)					Caregivers are encouraged to actively engage in discussions and seek advice and information	The caregiver support is provided via an online tool to be used remotely

#	Paper	Intervention	Purpose	Reactive	Episodic	Generic	Central	Predictive	Preventative	Personalised	Participatory	Decentralised
			and relationship with the care recipient.		users' own inclination	that is the same for all users					via the online support tool	
21	(Aloulou et al., 2013)	Ambient assistive living solution consisting of a set of sensors (e.g. pressure, proximity, vibration and motion sensors) and devices (e.g. speakers and tablets for the residents, smart-phones and a console for the caregivers) controlled by a software platform. The system monitors residents to detect wandering at night, falls, showering too long, and leaving the tap on; and responds by providing prompts/reminders to residents or notifying caregivers.	To improve efficacy and efficiency of care in nursing homes	The system detects events such as falls once they have taken places, then responds with a corresponding action such as eliciting help from a caregiver			The system is designed for and deployed in a nursing home			Requirements for the system include that it should be personalised and adaptive to fit individual residents' (users') habits and condition severity.		
22	(Blom et al., 2013)	'Mastery over Dementia': an internet-based intervention for caregivers of people with dementia that includes psycho-education, cognitive behavioural therapy, problem solving therapy, assertiveness training and relaxation in 8 sessions over (up to) 6 months.	To reduce depression, anxiety, caregiver burden, and perceived stress among dementia caregivers		The intervention is a once-off programme including 8 sessions plus a booster	The intervention is identical for all participants in terms of content, format, number of sessions.			The caregiver support intervention is aimed at preventing symptoms (e.g. depression, anxiety) among caregivers of people with dementia		Users (caregivers of people with dementia) receive feedback on their input and are guided through the programme.	The caregiver support intervention is internet-based for home-use
23	(García Vázquez et al., 2012)	e-Health service providing home-based cognitive stimulation therapy to people with Parkinson's disease using a TV set	To enable remote and thus more flexible therapy, thereby improving community health care services (and consequently autonomy) for people with							Cognitive therapy exercises are selected and customised by therapists according to the particular needs of each patient.		eHealth service for patients to carry out cognitive stimulation therapy at home using a TV set

#	Paper	Intervention	Purpose	Reactive	Episodic	Generic	Central	Predictive	Preventative	Personalised	Participatory	Decentralised
			cognitive disorders.									
24	(F. J. M. M. Meiland et al., 2012)	COGKNOW Day Navigator (CDN) assistive technology (stationary touch-screen, mobile device, sensors/actuators) that provides a calendar, reminders, picture dialling, music, activity assistance (instructions for daily activities), emergency services, safety warnings and navigation assistance.	To support people with dementia with memory, social contacts, daily activities and safety in daily life, thereby improving or maintaining their autonomy			The COGKNOW system is designed to meet general needs rather than to be tailored to fit individual users.				The COGKNOW Day Navigator offers a wide range of functionality, from which a patient could potentially select only that best suited to their individual needs.		The COGKNOW Day Navigator is designed for home-use as assistive technology outside of a clinical setting
25	(van Hoof et al., 2011)	An "unattended autonomous surveillance system" installed in patient homes to monitor mobility and detect emergency situations (fires, falls, wandering)	To support ageing-in-place by improving home safety for people with dementia.	The system triggers alarms and alerts help in response to detected emergencies (e.g. a fall or wandering out of the home).					The system includes wandering prevention by detecting door-opening events that trigger a phone call to confirm intent.	Functionality can be turned on/off for different users based on their needs. Settings can also be adjusted (e.g. delay after home exit before triggering a "wandering" alarm) for different levels of security.		The monitoring system is designed for users' homes as an ambient assisted living technology
26	(Van Der Marck et al., 2011)	The Falls Telephone makes automated, routine phone calls to users prompting them to report through the telephone the number of falls have had within a specified period.	Monitor fall occurrences (rates) over an extended period for research purposes or to inform users.	Falls are reported after they have occurred (not prevented).		The Falls Telephone has the same design and intended use for all users.						The Falls Telephone is used at home for remote monitoring (of falls)
27	(Van Der Roest et al., 2010)	DEMentia-specific Digital Interactive Social Chart (DEM-DISC) is a web-based tool that guides users in specifying their	To provide PwD and their caregivers with information about dementia and care services, thereby			The DEM-DISC intervention provides general information on available dementia care				The information provided by DEM-DISC is tailored to users' needs, which they specify as		DEM-DISC is used at home on users' personal computers

#	Paper	Intervention	Purpose	Reactive	Episodic	Generic	Central	Predictive	Preventative	Personalised	Participatory	Decentralised
		needs and provides general and tailored information (on diagnosing dementia, practical support, coping, and finding company).	improving their autonomy.			and welfare services (diagnosing dementia, practical support, coping, and finding company).				input to the system.		
28	(Hilbe et al., 2010)	BUCINATOR bed-exit-alarm system located at the side rails of nursing beds	To prevent bed-related patient falls			The bed-exit alarm is designed to be universally applicable, with a generic design and intended use for all users.	Designed for nursing beds in a hospital/care home setting		Falls are prevented by triggering an alarm before a fall is likely to occur, as the patient attempts to exit their bed.			
29	(Mihailidis et al., 2008)	COACH computerised device to guide people with dementia through the activities of daily living using audio and/or audio-video prompts	To support ageing-in-place among people with dementia and reduce the burden on their caregivers							The COACH system's behaviour (level of detail for prompting assistance) is adjusted for different users based on their cognitive status, performance and responsiveness.		The COACH system is designed for home use
30	(Shoval et al., 2008)	GPS tracking kit (RF watch, GPS mobile unit, and a home unit) to monitor out-of-home mobility patterns in people with dementia	To improve wellbeing among people with dementia and their caregivers by addressing decreased mobility associated with their condition			The GPS kit intervention is identical for all users in terms of its design and intended use.						The mobility monitoring intervention includes GPS kits that are used in home and community settings

B. Article: Pervasive assistive technology for people with dementia: a user-centred design case

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Pervasive assistive technology for people with dementia: a user-centred design case

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Smart mobile and wearable technology offers exciting opportunities to support people with dementia (PwD). Its ubiquity and popularity could even benefit user adoption - a great challenge for assistive technology (AT) for PwD that calls for user centred design (UCD) methods. This work describes a user-centred approach to developing and testing AT based on off-the-shelf pervasive technologies. A prototype is created by combining a smartphone, smartwatch and various applications to offer 6 support features. This is tested among 5 end-users (PwD) and their caregivers. Controlled usability testing was followed by field testing in a real-world context. Data is gathered from video recordings, interaction logs, system usability scale (SUS) questionnaires, logbooks, application usage logs, and interviews structured on the unified theory of acceptance and use of technology (UTAUT) model. The data is analysed to evaluate usability, usefulness and user acceptance. Results show some promise for user adoption but

1. Introduction: An ageing population spells a rise in the prevalence of dementia which will greatly impact quality of life for the elderly [1]. While assistive technology (AT) could potentially support people with dementia (PwD), it is highly fragmented with very low adoption in practice. An interesting solution may lie at arm's reach: readily available smartphones and wearables could be used to merge many of the roles of existing AT on a flexible and popular platform.

Mainstream pervasive technologies have successfully been applied in healthcare applications within the growing field of pervasive healthcare [2]. While opportunities for pervasive healthcare in dementia are extensive [3], little is known about whether PwD are interested in or able to use smart products since these predominantly target the young and healthy. For people in the early stages of dementia who live at home, these technologies are particularly interesting for keeping users independent and socially engaged.

Several works evaluate usability of AT for cognitively impaired users, however these tend to focus on specialised equipment developed for the impaired [4]. The aim of this work is therefore to investigate adoption among users with mild dementia of a pervasive AT solution using only off-the-shelf technology. We first develop a basic solution by selecting and combining a smartwatch, smartphone and applications (apps). This is tested among users to evaluate usability, usefulness and acceptance, highlighting key issues regarding smart mobile and wearable devices for PwD. The results are used to draw up recommendations for design and healthcare practitioners, identify adoption profiles and highlight important areas for future research.

1.1. User centred design (UCD) approach: UCD aligns neatly with a patient-centred care and is essential in developing successful AT for dementia, though it has often been overlooked [5]. Inclusive design and co-design are two related concepts that tie into UCD. Inclusive design has contributed substantially towards designing for elderly users over the years [6]. Research on co-design methods for users with cognitive impairment encourages involvement of end-users and the use of simple prototypes [7]. Several studies developing AT for dementia document a UCD approach that involves users and includes evaluation of usability and usefulness [8]–[12]. Though important, these examples apply UCD methods to develop specialised AT equipment rather than employ off-the-shelf solutions. In this work, we will instead focus on adapting consumer-grade pervasive technology. To do so, we employ a similar UCD approach that incorporates user testing guided by inclusive design [13], [14] and factors influencing technology adoption [15].

The people, activities, context and technology (PACT) framework [16] can guide the evaluation of a system involving human-technology interaction. Accordingly, user testing should involve the target group (*people*) using the *technology* for its intended purpose (*activities*) in realistic *contexts*. This can be achieved by combining different types of user testing in both a controlled environment and real-world context, such as usability testing and field testing [13].

The system usability scale (SUS) is a standardised questionnaire used to evaluate the perceived usability of the solution among the users [17], [18]. In addition to usability; perceived usefulness is also important for technology adoption among elders [19]. These relate to *complexity* and *relative advantage*, which are two characteristics of innovations that influence their adoption [20]. The unified theory of acceptance and use of technology (UTAUT) is an established model for evaluating technology adoption [21]. This includes questions on usefulness and usability, as well as on social influence, facilitating conditions, intention to use and use behaviour. These align with findings from a study on hearing aids (another AT that targets older users) in which adoption barriers included low perceived severity, stigmatisation, technology anxiety and low usability due to poor vision or dexterity [22]. The use of popular, pervasive technology could influence these factors when it comes to AT for dementia, and is described in the following section.

1.2. Pervasive assistive technology for dementia: AT for dementia covers a wide range of technological concepts including smart homes, tracking devices and interactive systems. These are used to provide functional support with memory and everyday activities, for social engagement or stimulation, and to improve safety and care. The use of pervasive computing for AT is referred to as pervasive assistive technology [2]. In this work, the focus is on smart mobile and wearable devices, specifically smartphones and smartwatches, which can serve as both interactive and tracking devices. These products are inherently flexible due to their modular nature: a device can employ different combinations of sensors and apps to serve a particular function or set of functions. The popularity, ubiquity and flexibility of pervasive products could enhance adoption among PwD. Compared to other specialised aids; we recognise the following key advantages offered by products such as smartphones and wearables:

- They are **less stigmatised** since they do not draw attention to the user's impairment.
- Increasingly in future, they will be **familiar** to users who already rely on these technologies in their everyday lives prior to their cognitive impairment, making them easier to learn to use.
- They are well known and **available** worldwide, making them more accessible than products that users may not be able to purchase in their home country – or may never hear of.
- Their flexibility lends itself to personalisation. Products can be selected and customised to **fit individual needs** and adapted as these change over time at minimal cost or effort (eg by installing a new app or adjusting settings).
- They are more "**future proof**". Changes or upgrades to the user's smartphone, wearable or apps as technology improves should not hinder the provision of continued functional support, except where version compatibility is affected.

AT should also meet users' support needs to be useful. Indeed, smart technology and wearables could meet many of the needs of PwD, their caregivers and healthcare providers. In earlier work, 4 main need areas have been identified as: functional, psychosocial, safety and care needs [23]. These were identified from literature as well as through needs gathering activities (interviews, observation, shadowing) involving multiple stakeholders (PwD, their caregivers and healthcare professionals). Many of the support features offered by existing AT to meet these need areas are readily available from common pervasive technology. A selection of 6 key support features includes:

a. *Scheduling*: calendars that provide an overview of a user's schedule and reminders for tasks and appointments [12], [24].
b. *Navigation*: assist a user in finding their way [25], [26]. This could also improve mobility and keep users socially engaged.
c. *Communication*: enabling users to easily contact their primary caregiver and others in their care and social networks [26]–[28].
d. *Orientation*: provide current time of day and location (temporal and spatial orientation), since a PwD can become disoriented [29].
e. *Emergency help*: provide a way for users to elicit help in the case of an emergency, such as a fall or when they are lost [26], [30].
f. *Monitoring*: gather behavioural data to measure indicators of the user's status and/or wellbeing [31], [32]. This can support healthcare professionals in delivering timely and appropriate care.

Table 1. Overview of software setup on the phone and watch to achieve 6 support features. *Abbreviations: Phone (P), Watch (W).*

Function	Application	Device	Purpose
Scheduling	Google Keep	P	Create notes and lists with reminders, displayed on phone screen using a widget
	Google Calendar	P	Manage schedule by entering appointments and events on the phone or web portal
	DigiCal Widget	P	Display schedule and notify about events on the smartphone screen
	Agenda	W	Calendar overview on smartwatch, synced with Google Calendar
Navigation	Google Maps	P,W	Route planning and turn-by-turn navigation
Communication	Contact Widget	P	Shortcut to call primary caregiver displayed on the home screen
Orientation	AccuWeather	P	Display time and location on home screen
	Custom watchface	W	Display time of day (eg “Thursday afternoon”) together with time on watchface
Emergency Help	If This Then That	W,P	Shortcut for user to send caregiver an emergency message with their location Notify caregiver when the user leaves a predefined safe-zone
Monitoring	Moves	P	Track user’s mobility (out of home)
	Fit	P, W	Track user’s activity levels (in and out of home)

There are many other roles of AT for dementia that could be fulfilled using pervasive technology, eg fall detection, activity recognition, life-logging and reminiscence therapy to name a few [5], [33], [34]. The above support features are selected as a starting point based both on being relatively simple to implement with available apps and offering considerable benefit for users.

2. Equipment selection and adaptation: The equipment selected to fulfil the support features outlined in the previous section includes a smartphone and smartwatch used in combination with various apps. The smartphone provides a familiar interface through which users can input data and carry out tasks. The smartwatch provides a second interface and wearable sensors located on the wrist. This is especially relevant for PwD who may have difficulty remembering, since the user need not remember to carry their smartphone on them at all times in their home. Inclusive design and personalisation were focal points in the selection of devices and influenced the choice of operating system (OS) and physical hardware.

Personalised support that fits the user and their individual needs is important for user adoption. In choosing an operating system, this meant considering device compatibility, support for a wide range of apps and adaptability; based on which the Android platform was selected. All smartwatches built with the Android Wear platform are compatible with Android 4.3+ or iOS 8.2+, offering a wider selection of watch designs than Apple’s iOS. Android (and Android Wear) also offer a wide selection of apps, and greater opportunity for adaptation and customisations.

Inclusive design guided the hardware selection. Primary end-users include the PwD and their caregivers (usually a spouse or child) indicating an elderly user group, since most PwD are over 65 years old. Capabilities of elderly users such as their vision, hearing and dexterity relate to usability principles such as visibility, affordance and feedback [13]. This led to the following priorities: a large screen for visibility; touch input rather than buttons for improved affordance; tactile feedback and the ability to provide haptic (vibration) notifications. Battery life exceeding 1 day was also considered important such that the user can routinely charge the device at night. This takes into account the PwD’s memory impairment, since structured routines make tasks easier to remember. Based on these considerations, the Sony Smartwatch 3 and Sony Xperia E4 devices were selected and are shown in Figure 1. The smartwatch runs Android Wear and the smartwatch Android OS v4.4.4.

Figure 1 *Selected hardware: Sony SmartWatch 3 (left) and Sony Xperia E4 (right)*

Following hardware selection, the devices were adapted to meet each of the 6 support features described in Section 1.2. This involved installing selected off-the-shelf apps and widgets, and customising the phone and watch home screens. An overview of the software setup used to provide each support feature is outlined in Table 1. Of these, *monitoring* was not tested further, since this is not used directly by the PwD or caregiver. It is included up to this point to indicate how the pervasive AT solution could be applied to gather data for further measurement, since this is of great interest among AT for dementia.

3. User testing: The prototype was tested with target users both in a controlled setting and a real-world context. Participants were recruited through a dementia clinic at a Danish hospital and participated together with their spouses as pairs. The only criterion for inclusion was a diagnosis of MCI or mild dementia, since this is the target group for the pervasive AT which should be introduced as early as possible in the disease process. Participation was voluntary and with informed consent. In total 6 pairs were recruited and will be referred to using the codes P1 to P6 (for PwD numbered 1-6). P4 dropped out at the start and the remaining 5 pairs included 3 male and 2 female PwD between the ages of 61-73 years, 4 of which claim to use a smartphone daily (2 Android, 2 iOS) and 1 with no experience.

The user testing was implemented in two phases: usability testing and field testing. The goal of the usability testing is to identify key usability issues and their causes. This was facilitated by a project member and followed a predefined protocol involving 13 tasks over ~2 hours in a controlled environment (see Figure 2). Interaction logs and video recordings were used to collect data on task completion rates, and on the frequency and severity of errors or problems. A SUS questionnaire was used to assess perceived usability at the end of each phase.

The field testing allowed testing “in the wild”. In this phase, the participant pairs took the devices home and used them unsupervised for one week. The goal of field testing was to assess perceived usability and usability issues in real life, and to assess acceptance and use, and any issues that influence these. Several methods were used to collect data: participants kept logbooks to note down issues and experiences, application usage was logged on the devices, and a semi-structured debriefing interview was performed. The debriefing interview was guided by the UTAUT model and also included a repeat of the SUS questionnaire.

Figure 2 *Participants performing tasks on the smartwatch during the usability testing*

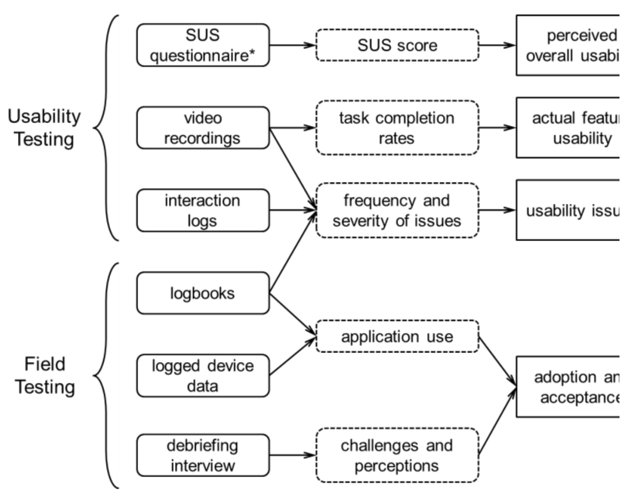


Figure 3 *Overview of the data collection methods for each part of the testing. *SUS was repeated during the debriefing interview following field testing.*

4. Analysis and results: Data collected in the user testing was analysed to evaluate: perceived overall usability, actual usability by support feature, key usability issues and user acceptance. Figure 3 provides an overview of the various data sources and how these contribute to these analyses.

4.1. Perceived overall usability: The SUS score measured the user’s perception of the usability of the system as a whole following both the usability and field tests. P1 did not attend the debriefing, therefore both scores are only available for 4 participants. The results are shown in Figure 4, which indicates that agreement among participants regarding perceived usability was higher after the field testing. SUS scores decreased following the field testing for 3 participants, with only P3’s improving (however this was extremely low at the usability test). Interestingly, P3 was also the only participant without prior experience using a smartphone.

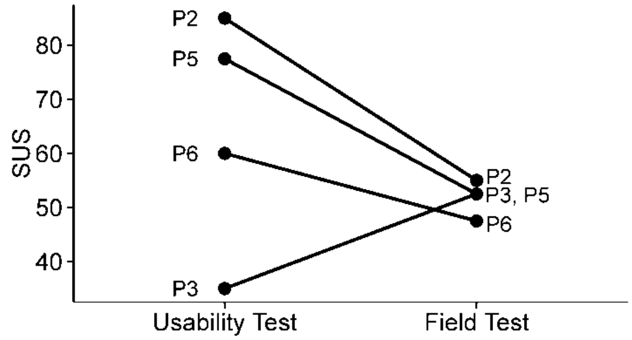


Figure 4 *System usability scores (SUS) for 4 participants, measured after the usability testing and then after the field testing.*

4.2. Actual usability by feature: Video recordings of the usability testing were analysed to calculate completion rates for each of the tasks performed by the participants. The tasks relate to the features described in Section 1.2 (scheduling, navigation, communication, orientation, emergency help), as well as to more general use of the smartphone and smartwatch. This complements the SUS scores by providing objective information on usability and detailing this for specific aspects of the prototype rather than the overall system. The task completion rates were organised into 3 tiers according to whether they were completed by all participants, some participants or no participants. An overview of the results is provided in Table 2, indicating which support feature relates to the tasks listed.

Table 2. Completion rates for tasks performed by users during the usability testing, given as the number of participants who successfully completed the tasks out of a total of 5 participants.

Feature	Tasks	Completion Rate
Scheduling:	Use calendar	5/5
	Notifications	
Communication:	Call partner	
Orientation:	Orientation	
General:	Unlock screen	
	Equip watch	
General:	Charge watch	4/5
Scheduling:	See agenda	2/5
	Use to-do list	
Emergency help:	Use emergency contact	0/5
Navigation:	Navigation	

4.3. Key usability issues: Data on problems or errors was collected from the facilitator’s interaction logs (usability testing) and participants' logbooks (field testing). This was analysed according to both frequency and severity of usability issues to identify the most critical issues. These are described below, grouped according to the task or component to which they relate.

a. Smartphone and smartwatch interfaces:
   i. Swiping: user does not intuitively swipe to see widgets on the smartphone, or know when to stop swiping through the menu on the smartwatch.
   ii. Home screens/watchfaces: users accidentally edit or delete home screens (phone) and watchfaces (watch) by pressing them for too long.

b. Smartwatch charging: users had difficulty locating the charging port and inserting the cable

c. Navigation: users need to start moving in order to calculate their direction, causing them to start off in the wrong direction.

d. Smartphone calling: users familiar with smartphones used the contact book rather than the shortcut to call their caregiver.

e. Reminders and notifications:
   i. Reminders require different notice periods (eg a doctor appointment requires time to prepare and travel, medication reminders do not), which was confusing for users to handle.
   ii. The use of multiple apps (Google Calendar, Google Keep, DigiCal and Agenda) for *scheduling* caused confusion.
   iii. Several participants recorded blank notes in Google Keep, possibly due to voice enabled note-taking on the smartwatch.

f. Device pairing: the Bluetooth connection between the phone and watch drops unexpectedly; or is completely lost, requiring a factory reset on the smartwatch to be re-established.

g. Unintuitive application names/icons: users had difficulty finding the functionality they were looking for based on the icon/name, eg where the application If This Then That (IFTTT) was used to create an emergency help feature.

4.4. User adoption and acceptance: The analysis of user adoption and acceptance is based on data collected in the field testing only. Data on app usage was logged on the devices throughout the field testing as an indication of how much participants actually used the solution, which is depicted in Figure 5. During the debriefing interview, participants were asked whether they found the prototype useful and easy to use, if they felt encouraged to use it by their social/care network, were adequately supported in using it, and about their intention to use the prototype further (as per the UTAUT model).

Information from the logged data, debriefing interview and general participant feedback was used to place the participants within four identified adoption profiles summarised in Table 3. For P1 and P4 (Profile C), usability was a key adoption barrier that even prevented them from participating for the duration of the study. P2 and P3 (Profile B) were able to use the prototype but felt they did not need it or preferred their current strategy (eg using a wall calendar). Here low utility or usefulness is the key barrier. More specifically, the solution does not replicate familiar or established methods. Profile A includes P5 and P6 who accepted the solution and wished to use it further. These profiles refer to two broad adoption barriers: usability and usefulness. Usability is dealt with in detail through the previous analyses. Regarding usefulness, several key points were noted from participant feedback:

- None of the participants felt that they needed the navigation support
- Reminders were considered highly useful by both participants who wished to continue using the prototype (Profile A)
- Interoperability was a considerable barrier for the iPhone user

These collected findings and their implications for practitioners and future research efforts are discussed in the following section.

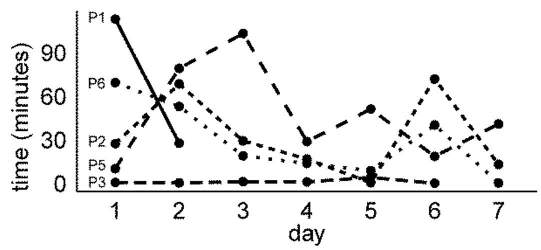


Figure 5 *Time participants spent using the AT solution during field testing based on logged app use.*

Table 3. Adoption profiles based on data collected during the debriefing interviews.

		Usability	
		-	+
Usefulness	-	**Profile D: no participants** Neither able to use nor interested in using the prototype.	**Profile B: P2, P3** Used the prototype for the study, but concluded that they did not need it.
	+	**Profile C: P1, P4** Interested in using the prototype, but found it too overwhelming.	**Profile A: P5, P6** Used the prototype and wished to continue.

5. **Discussion:** Our findings have uncovered valuable insights regarding both the methods and results. Key lessons from our methods can contribute towards best practices for a UCD approach to developing smart, pervasive AT for dementia. Our findings in terms of usability, usefulness and user adoption can be used to improve future design endeavours.

5.1. UCD for developing smart, pervasive AT: We have employed a user-centred approach in the development and testing of a pervasive AT solution. Inclusive design guided the selection technology for a first simple prototype even before end-users were involved by relating specifications (eg screen size, buttons) to users' capabilities. More importantly, we have demonstrated how involving end-users in various testing methods can generate valuable design insights.

The combination of methods used provided information on 3 different aspects of usability: perceived overall usability, actual usability for different support features, and usability issues. These complemented each other, providing distinct and valuable information at increasing levels of detail. SUS scores gave an impression of overall usability from the end-user's perspective. Task completion rates – an indication of actual usability – highlighted which support features were more usable than others. Investigating specific usability issues added depth to these results by providing clues as to *why* these features were not usable, offering directions for future designs.

The importance of field testing "in the wild" was highlighted by the compared SUS scores. These tended to be both lower and more similar following the field testing, suggesting a more realistic indication of users' perceptions. The field testing also allowed deeper insight into usefulness, since it depends on users choosing to use the solution rather than prescribed tasks or try to imagine whether they would use it. In summary, we recommend the following practices for user-centred development of pervasive AT:

- Including both controlled and real-world testing conditions
- Combining subjective data (participants perceptions) with objective measures
- Using multiple testing methods for varying levels of detail on key issues and their possible causes

5.2. Usability, usefulness and user acceptance: Usability and usefulness were focal points of this research because of their known influence on adoption among elderly users. The user testing yielded interesting findings in each of these areas.

Regarding perceived overall usability, the participant without previous experience using a smartphone (P3) was particularly noteworthy. Despite extremely poor initial perceptions of usability (SUS score), this improved to the level of the other participants after a week's field testing. This promising result indicates that experience is not a prerequisite for smart technology to be perceived as usable.

For specific support features, our findings suggest that the *scheduling*, *communication* and *orientation* features were usable, whereas the *navigation* and *emergency help* features were clearly not usable at all. Digging deeper into the issues that inhibit usability raises the question of who should use this information. Here we recognise a distinction between designers of the existing hardware or software, and designers of the pervasive AT concept. Issues such as device pairing or battery charging can inform the design of the pervasive technologies, such that they might be more inclusive in future. Issues such as using multiple apps for a single support feature, or accidentally recording blank Google Keep notes can inform the customisation of these pervasive technologies to serve as AT for PwD. A key takeaway was that the smartwatch has poor usability as an input device, and should be used for notifications, orientation and possibly monitoring (gathering sensor data) only.

Regarding usefulness, again *scheduling* stands out as most appealing and *navigation* the least. This may be due to the PwD being in the early stages, during which getting lost may not be a concern. Usefulness was a draw factor for the two adopters, underscoring the need to meet users' needs. Overall, our findings show some promise for user adoption of the pervasive AT solution, with usability and usefulness both being significant factors.

Two central aspects that emerged were *familiarity* and *personalisation*. Participants tend to prefer what they are familiar with – a *"go with what you know"* attitude. This is evident in the tendency to choose the contact book over the calling shortcut to call their caregiver, confusion over swiping (which may not be as familiar as pressing buttons) and a preference for one's current scheduling solutions. Choosing hardware and software that are most aligned with what users are used to could therefore improve both usability and perceived usefulness, and ultimately adoption. Regarding personalisation, this study tested a standard set of support features rather than a set tailored to each participant's preferences. By including only those solutions that the user is interested in, the solution may be less overwhelming and seem more relevant. The following recommendations summarised the complete findings:

- The smartphone should be used for input and the smartwatch for output (eg notifications, orientation and behaviour sensing).
- Scheduling (including notes, reminders and notifications) are most promising in terms of both usability and usefulness
- Navigation and emergency support were not perceived as useful or usable.
- Familiarity is an important design consideration since users tend to have a *go with what you know* approach.
- The solution should be personalised to include only those support features that the user deems relevant for their individual needs

5.3. Limitations and future work: The user testing methods were time consuming in terms of data collection and analysis, limiting the number of participants. PwD vary substantially regarding symptoms, lifestyle, background and technology literacy etc – all of which may influence adoption – therefore it is not possible to make broad generalisations about user adoption of the pervasive AT solution. Instead, our results provide a first impression, showing some promise for user adoption and pinpointing key issues for further study.

Extending the field testing over months would allow greater insight into use patterns than were possible for 1 week. Long term testing could be used to explore whether use and acceptance improve over time with learning and habit or whether it drops as the novelty wears off or the user's condition worsens, and uncover issues such as whether users are able to routinely charge the devices. Another interesting avenue would be to tailor the pervasive AT to individual needs, which was excluded to allow comparison of the same solution across participants.

Regarding the pervasive AT solution, though highly promising, this cannot replace all other forms of AT (eg home automation equipment or animaloid robots). Furthermore, while a wrist-worn device may be easier to remember than a smartphone, it is not fool-proof. Removing and forgetting the device is still a concern. The monitoring capabilities were not tested in this work. Behavioural measurement could support timely and targeted intervention, improving the quality of care, therefore extensive research – including user testing methods – are required in this area.

Finally, implementation in clinical practice is emphasised as an important area of future research, since this is a significant challenge for wearable technology in healthcare [32]. Strategies for healthcare providers to introduce pervasive AT to PwD and integrate them into care practices are needed to accelerate and support adoption.

6. **Conclusion:** This work describes the development and testing of a pervasive AT solution created by combining off-the-shelf smart technology. These devices offer advantages over specialised AT regarding user adoption, motivating an evaluation of their usability, usefulness and user acceptance.

A smartphone, smartwatch and several apps were combined to offer 6 support features, including: scheduling, communication, orientation, navigation, emergency help and monitoring. This was tested with 5 participants with mild dementia and their spouses through usability testing and field testing. SUS scores, task completion rates, interaction logs and user feedback were analysed to evaluate perceived and actual usability, and to pinpoint key usability issues. Logged usage and semi-structured interviews based on the UTAUT model were analysed to assess usefulness and to identify four main adoption profiles.

The results showed promise for user adoption overall, with scheduling as most successful and navigation least in terms of usability and usefulness. Based on our findings, we contribute with suggested UCD practices for developing pervasive AT such as combining test methods, including end-users' perceptions and testing in a real-world context. A set of recommendations for future designs is also provided based on our results, including: using the smartwatch as output only, personalising the solution to users' individual needs, and making it as familiar to them as possible. There are still challenges ahead that call for further research on long term adoption patterns, behavioural monitoring and clinical implementation. The ultimate vision is pervasive, person-centred care to support people with dementia and improve their quality of life.

7. **Acknowledgements:** We would like to acknowledge VihTek for their generous contribution of equipment, as well as Eva Bjerregaard and her colleagues from the dementia and memory clinic at Rigshospitalet-Glostrup, without whom our research would not be possible.

8. References

[1] M. Prince, A. Wimo, M. Guerchet, A. Gemma-Claire, Y.-T. Wu, and M. Prina, "World Alzheimer Report 2015: The Global Impact of Dementia - An analysis of prevalence, incidence, cost and trends," *Alzheimer's Dis. Int.*, p. 84, 2015.

[2] J. E. Bardram, "Pervasive healthcare as a scientific discipline.," *Methods Inf. Med.*, vol. 47, no. 3, pp. 178–85, Jan. 2008.

[3] M. D. Mulvenna, C. D. Nugent, F. Moelaert, D. Craig, R. M. Dröes, and J. E. Bengtsson, "Supporting people with dementia using pervasive health technologies," in *Advanced Information and Knowledge Processing*, vol. 47, 2010, pp. 3–14.

[4] E. Lindqvist, T. J. Larsson, and L. Borell, "Experienced usability of assistive technology for cognitive support with respect to user goals," *NeuroRehabilitation*, vol. 36, pp. 135–149, 2015.

[5] A. J. Bharucha, V. Anand, J. Forlizzi, M. A. Dew, C. F. I. I. I. Reynolds, S. Stevens, and H. Wactlar, "Intelligent Assistive Technology Applications to Dementia Care: Current Capabilities, Limitations, and Future Challenges," *Am. J. Geriatr. Psych*, vol. 17, pp. 88–104 10.1097/JGP.0b013e318187dde5, 2009.

[6] P. John Clarkson and R. Coleman, "Designing for our future selves," *Appl. Ergon.*, vol. 46, pp. 233–234, 2015.

[7] K. Slegers, P. Duysburgh, and N. Hendriks, "CoDesign with people living with cognitive and sensory impairments," *CoDesign*, vol. 11, no. 1, pp. 1–3, Jan. 2015.

[8] I.-L. Boman, S. Lundberg, S. Starkhammar, and L. Nygård, "Exploring the usability of a videophone mock-up for persons with dementia and their significant others.," *BMC Geriatr.*, vol. 14, no. 1, p. 49, Jan. 2014.

[9] F. J. M. Meiland, A. I. E. Bouman, S. Sävenstedt, S. Bentvelzen, R. J. Davies, M. D. Mulvenna, C. D. Nugent, F. Moelaert, M. E. Hettinga, J. E. Bengtsson, and R.-M. Dröes, "Usability of a new electronic assistive device for community-dwelling persons with mild dementia.," *Aging Ment. Health*, vol. 16, pp. 584–91, 2012.

[10] V. Leuty, J. Boger, L. Young, J. Hoey, and A. Mihailidis, "Engaging older adults with dementia in creative occupations using artificially intelligent assistive technology.," *Assist. Technol.*, vol. 25, no. 2, pp. 72–79, 2013.

[11] R. J. Davies, C. D. Nugent, M. P. Donnelly, M. Hettinga, F. J. Meiland, F. Moelaert, M. D. Mulvenna, J. E. Bengtsson, D. Craig, and R.-M. Dröes, "A user driven approach to develop a cognitive prosthetic to address the unmet needs of people with mild dementia," *Pervasive and Mobile Computing*, vol. 5. pp. 253–267, 2009.

[12] A. M. Maier, A. G. Özkil, M. M. Bang, B. Hysse Forchhammer, and B. H. Forchhammer, "Remember to remember: A feasibility study adapting wearable technology to the needs of people aged 65 and older with Mild Cognitive Impairment (MCI) and Alzheimer's Dementia," in *Proceedings of International Conference on Engineering Design (ICED 2015)*, 2015, vol. 1 BT - Pr, pp. 331–340.

[13] J. Preece, Y. Rogers, and H. Sharp, *Interaction design : beyond human-computer interaction*. J. Wiley & Sons, 2002.

[14] J. Clarkson and R. Coleman, "Inclusive design," *J. Eng. Des.*, vol. 21, no. 2, pp. 127–129, Apr. 2010.

[15] V. Venkatesh, "User acceptance of information technology: Toward a unified view," *MIS Q. Manag. Inf. Syst.*, vol. 27, no. 3, 2003.

[16] D. Benyon, *Designing interactive systems : a comprehensive guide to HCI and interaction design*, 2nd ed. Addison Wesley, 2010.

[17] J. Brooke, "SUS - A quick and dirty usability scale," *Usability Eval. Ind.*, vol. 189, no. 194, pp. 4–7, 1996.

[18] "System Usability Scale (SUS)," 2013. [Online]. Available: https://www.usability.gov/how-to-and-tools/methods/system-usability-scale.html. [Accessed: 28-Jun-2016].

[19] V. L. Hanson, "Influencing technology adoption by older adults," *Interact. Comput.*, vol. 22, pp. 502–509, 2010.

[20] E. M. Rogers, *Diffusion Of Innovations, 4Th Edition*. Free Press, 2010.

[21] F. D. . D. Viswanath Venkatesh , Michael G . Morris , Gordon B . Davis, V. Venkatesh, M. G. Morris, G. B. Davis, and F. D. Davis, "User acceptance of information technology: Toward a unified view," *MIS Q.*, vol. 27, no. 3, pp. 425–478, 2003.

[22] C. Meyer and L. Hickson, "What factors influence help-seeking for hearing impairment and hearing aid adoption in older adults?," *Int. J. Audiol.*, vol. 51, no. 2, pp. 66–74, 2012.

[23] J. R. Thorpe, B. H. Forchhammer, and A. Maier, "Needs Elicitation for Novel Pervasive Healthcare Technology," *14th International Design Conference - Design 2016*. Design Society, pp. 1947–1956 BT – 14th International Design Conferen, 2016.

[24] F. J. Meiland, A. Reinersmann, B. Bergvall-Kareborn, D. Craig, F. Moelaert, M. Mulvenna, C. Nugent, A. Scully, J. Bengtsson, and R. M. Dröes, "COGKNOW: Development of an ICT device to support people with dementia," vol. 5, no. 5, pp. 324–334, 2007.

[25] D. J. Patterson, L. Liao, K. Gajos, M. Collier, N. Livic, K. Olson, S. Wang, D. Fox, and H. Kautz, "Opportunity Knocks: a System to Provide Cognitive Assistance with Transportation Services," *Int. Conf. Ubiquitous Comput. (UbiComp}*, pp. 433–450, 2004.

[26] L. Robinson, K. Brittain, S. Lindsay, D. Jackson, and P. Olivier, "Keeping In Touch Everyday (KITE) project: developing assistive technologies with people with dementia and their carers to promote independence.," *Int. Psychogeriatr.*, vol. 21, no. 3, pp. 494–502, Jun. 2009.

[27] I.-L. Boman, L. Nygård, L. Rosenberg, L. Nygard, and L. Rosenberg, "Users' and professionals' contributions in the process of designing an easy-to-use videophone for people with dementia.," *Disabil. Rehabil. Assist. Technol.*, vol. 9, no. 2, pp. 164–172, Mar. 2014.

[28] V. Perilli, G. E. Lancioni, D. Laporta, A. Paparella, A. O. Caffò, N. N. Singh, M. F. O'Reilly, J. Sigafoos, D. Oliva, A. O. Caffo, N. N. Singh, M. F. O'Reilly, J. Sigafoos, and D. Oliva, "A computer-aided telephone system to enable five persons with Alzheimer's disease to make phone calls independently," *Res. Dev. Disabil.*, vol. 34, no. 6, pp. 1991–1997, Jun. 2013.

[29] P. . Topo, K. . Saarikalle, E. . Begley, S. . Cahillb, T. . Holthe, and J. . Macijauskiene, "'I don't know about the past or the future, but today it's Friday' - Evaluation of a time aid for people with dementia," *Technol. Disabil.*, vol. 19, no. 2–3, pp. 121–131, 2007.

[30] M. Rowe, S. Lane, and C. Phipps, "CareWatch: a home monitoring system for use in homes of persons with cognitive impairment," *Top. Geriatr. Rehabil.*, vol. 23, pp. 3–8, 2007.

[31] V. Ahanathapillai, J. D. Amor, Z. Goodwin, and C. J. James, "Preliminary study on activity monitoring using an android smart-watch," *Healthc. Technol. Lett.*, vol. 2, no. 1, pp. 34–39, 2015.

[32] H. Lewy, "Wearable technologies – future challenges for implementation in healthcare services," *Healthc. Technol. Lett.*, vol. 2, no. December 2014, pp. 2–5, 2015.

[33] R. Luque, E. Casilari, M.-J. M.-J. Morón, G. Redondo, M.-J. Moron, M.-J. M.-J. Morón, and G. Redondo, "Comparison and characterization of android-based fall detection systems," *Sensors (Switzerland)*, vol. 14, no. 10, pp. 18543–18574, Oct. 2014.

[34] B. Kikhia, J. Hallberg, K. K. Synnes, and Z. ul H. Sani, "Context-aware life-logging for persons with mild dementia.," *Conf. Proc. ... Annu. Int. Conf. IEEE Eng. Med. Biol. Soc. IEEE Eng. Med. Biol. Soc. Annu. Conf.*, vol. 2009, pp. 6183–6186, 2009.

C. Field study: Data collection activities

Observation of patient consultations at the dementia and memory clinic, Rigshospitalet-Glostrup, and home visits within partner municipalities:

Date	Consultation	Caregiver present
05-01-2015	First meeting	Daughter
05-01-2015	Control	Wife
06-01-2015	Neuropsychological exam	Daughter
07-01-2015	First meeting	None
07-01-2015	First meeting	Wife
08-01-2015	First meeting	Husband
08-01-2015	First meeting	Daughter and son
09-01-2015	First meeting	None
09-01-2015	First meeting	None
26-03-2015	Home visit	Wife
22-04-2015	Home visit	Daughter
18-06-2015	First meeting	None
18-06-2015	First meeting	Son

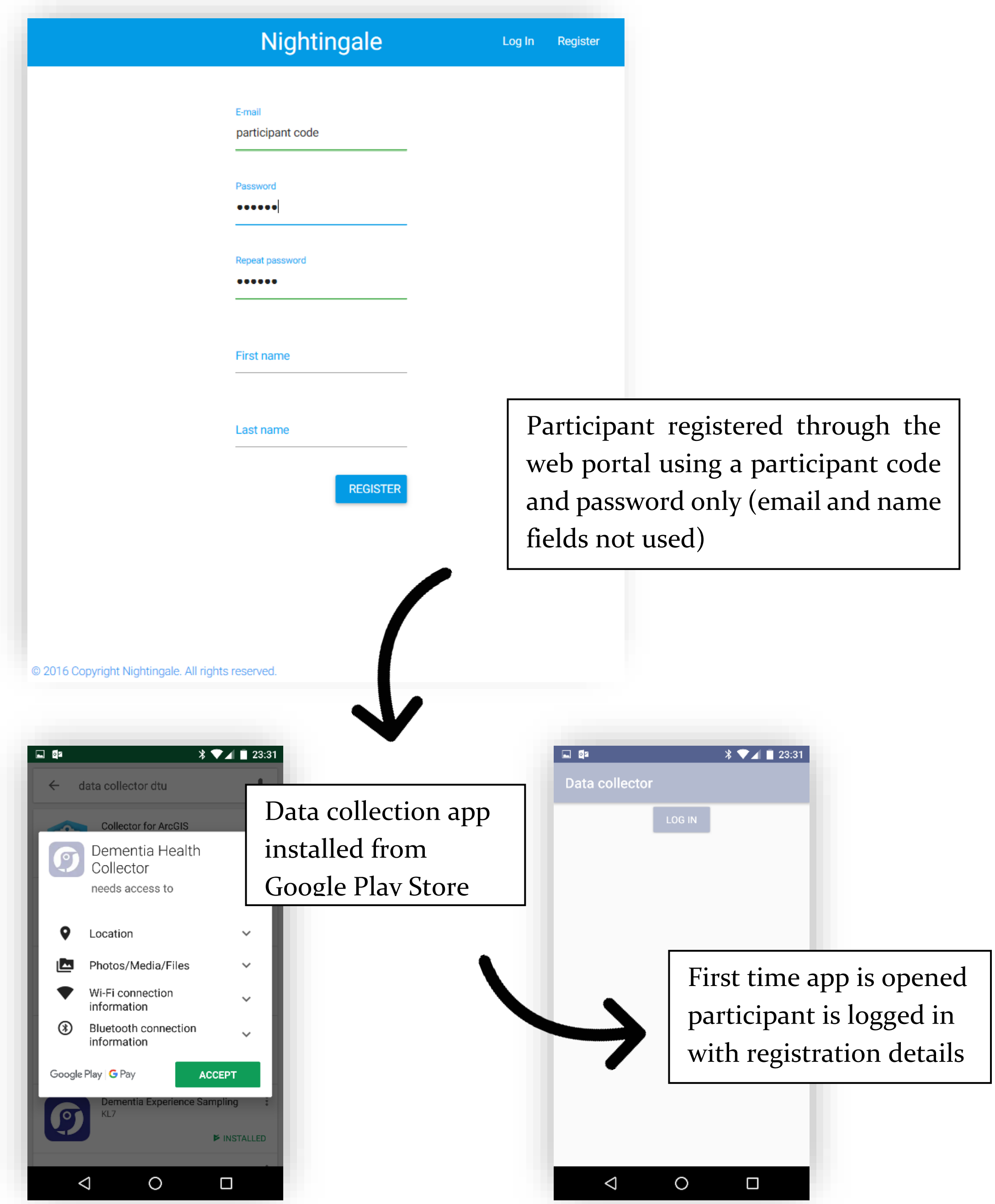
Interviews with healthcare professionals from the dementia and memory clinic, Rigshospitalet-Glostrup, and partner municipalities:

Date	Role
26-03-2015	Dementia consultant
22-04-2015	Dementia consultant
17-06-2015	Nurse
17-06-2015	Nurse
24-06-2015	Specialist doctor
24-11-2015	Neuropsychologist

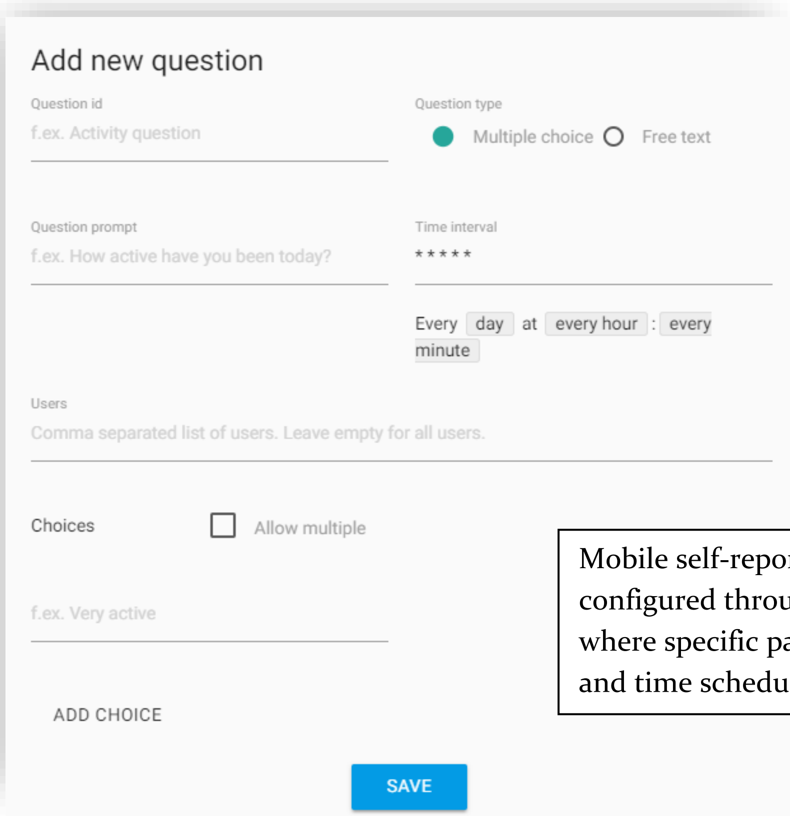
D. Custom applications for collection of sensor data and administering mobile self-reports

Custom applications (apps) were developed in collaboration with external contractors for collecting data from smartphones and smartwatches in this research. The following figures illustrate the process employed (I) to initiate data collection for each new participant, and (II) to configure mobile self-report questions.

I. Setting up data collection for a new participant

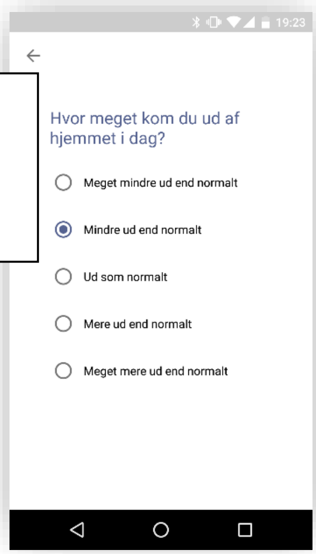


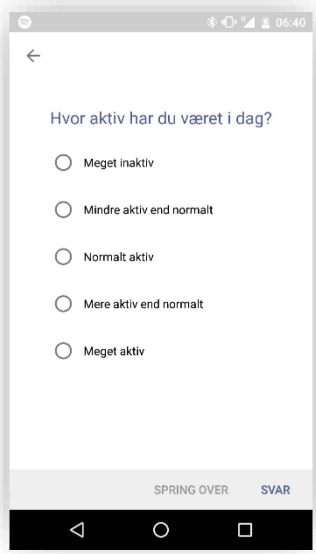
II. Setting up mobile self-report questions:



Mobile self-report questions are configured through the web portal, where specific participants (users) and time schedule are set up.

Participants receive prompts to answer scheduled mobile self-reports.





E. Code overview for behavioural monitoring algorithms

The following shows an R markdown file used to extract behavioural features (mobility and activity measures) from sensor data including location, activities and steps. The file calls separate modules (for GPS trajectory extraction and for daily step count) shown below, and custom functions written for e.g. the detection of stay events in location data. This appendix is intended to provide an impression of the code structure in terms of available modules and functions and the features these generate.

Engineering systems design in healthcare - Behavioural feature extraction

Julia Thorpe

October 2018

This work is conducted as part of the PhD project "Engineering Systems Design in Healthcare" at the Technical University of Denmark (DTU) in collaboration with Rigshospitalet-Glostrup. The project investigates the use of smart mobile and wearable technology for support and monitoring in dementia rehabilitation. The code below is used to extract a set of mobility features from location data and activity features from recognised activity and step count data.

Setup

Loads required packages and custom functions

Select participants to include and set input variables for the feature extraction algorithms:

```
# Select participant
p.codes <- c("P03JJ") # singel case for demo/testing
#p.codes <- c("P03JJ", "P06SS", "P07MG", "P08UH", "P10JL", "P13NB") # case studies
#p.codes <- c("daisy","violet","agapantha","anthurium","nasturtium") # pilot

# Set input variables:

# location / mobility
loc.accuracy <- 25  # threshold for accuracy of location points in meters
dT <- 5             # delta T, time window in minutes (stay detection)
dD <- 100           # delta D, diagonal distance boundary in meters (stay detection)
time.threshold.stay <- 10 # minimum duration of a stay, in minutes
time.threshold.go <- 5    # cut-off for filtering out "go" events to/from same location, in minutes
dist.threshold <- 50      # distance in meters within which two centroids belong to same stay location
Qd <- .99                 # quantile of distances to include in the minimum convex polygon
#doi <- as.POSIXct("2018-01-30") # day of interest (use when not d.start)

# activity
win.size <- 15 # window size in minutes for bout detection from step data
acts <- c("Still", "Foot", "Vehicle", "Bicycle") # specify activities of interest
```

Save device data that used for other purposes than extracting behavioural features (battery, screen, mobile self-reports).

Feature extraction

Mobility Features

Location data is used to extract mobility features. Inputs include: * GPS log file (dataframe) with the following data: latitude, longitude, timestamp * loc.accuracy for filtering data with low location accuracy * thresholds defined above for trajectory extraction module (see "mod_traj" script) Ouputs include: * home: estimated coordinates for persons home location * gps.traj: original GPS log file with columns appended for if the point is a stay/move, event number (in sequence throughout day), location ID and distance to home * traj.summary: summary of gps.traj by event, including columns for event duration, centroid (stays only), whether it is home, displacement from previous event (stays only), maximum action range * mob.metrics: all mobility metrics calculated by day (output below gives column names)

```
for(p in p.codes){

  # unpack participant data
  P <- participants[[p]]
  list2env(P, .GlobalEnv); remove(P)
  d.study <-  as.numeric(round(difftime(d.stop, d.start, units = "days"))) # partic
  datasets.all <-  readRDS(paste0("./output_data/datasets_", p, ".Rds"))

  # get location data
  gps.log <- datasets.all$location %>%
  filter(accuracy <= loc.accuracy) %>% # filter low accuracy GPS readings
  select(lat, lon, timestamp, intervals.alt, dates, times) #intervals.alt optional

  # get distances between points
  gps.log %<>% mutate(displacements =
                        c(0, distGeo(gps.log %>% select(lon, lat),
                                     a = 6378137, f = 1 / 298.257223563)))

  # get trajectories and metrics
  source("./Rscripts/mod_traj.R")               # runs module to extracts "stay" and "move" events from location data
  mob.metrics <- get_metrics(traj.summary, gps.traj) # calculates behavioural metrics (by day)
  mob.zones <- mobility_zones(traj.summary)         # calculates mobility zones entered as in questionnaire assessment (not
in use)

}

names(mob.metrics)
```

```
# -------------------------------------------------
# MODULE: MOBLITITY // TRAJECTORY EXTRACTION
#
# This module detects "stay" and "move" events from raw location data. The
# script below calls custom functions from jrt_mobility for detecting a home
# location, detecting stay events, inferring location ID's and cleaning the
# results.
#
# -------------------------------------------------

# Calculate home coordinates based on location data
home <- find_home(gps.log,"lat","lon")

# Extract trajectories: get series of stay/go events ("mobility traces")
gps.traj <- gps.log %>% group_by(dates) %>%
  do(get_trajectories(.,
                      dT = dT,
                      dD = dD,
                      T.stay = time.threshold.stay,
                      T.go = time.threshold.go,
                      dist.threshold = dist.threshold))
remove(gps.log)

# Update home location based on all stays that are home (stay points close to current home estimation)
home <- update_home(df=gps.traj,home=home,dist.threshold = dist.threshold)

# Add "distance to home" column for all points (in trajectories dataframe)
gps.traj %<>% ungroup(gps.traj) %>%
  mutate(homedist = distGeo(home,
                            ungroup(gps.traj) %>% select(lon,lat),
                            a=6378137, f=1/298.257223563))

# add columns for action range and displacement, and summarise data by trajectory segment/event
traj.summary <- summarise_trajectories(gps.traj=gps.traj,
                                       dist.threshold=dist.threshold)
```

[calls custom mobility functions]

```
## [1] "dates"     "AR.max"    "AR.mean"   "dist.total" "dist.foot"
## [6] "dist.max"  "Tt.move"   "Tm.move"   "Tt.out"     "N.moves"
## [11] "N.stay.out" "N.places" "mcp.area"
```

```r
# clear environment
remove(loc.accuracy, dT, dD, time.threshold.stay, time.threshold.go, dist.threshold, Qd)
```

Steps

Calculates total daily steps for each device. An alternative to the cumulative count signal is also generated showing number of steps per window for equal sized windows throughout the day. (Ultimatey, this was not used due to erratic step count updates).

```r
#, eval=FALSE, include=FALSE

for(p in p.codes){

  # unpack participant data
  P <- participants[[p]]
  list2env(P, .GlobalEnv); remove(P)
  d.study <- as.numeric(round(difftime(d.stop,d.start,units="days"))) # participation
  datasets.all <- readRDS(paste0("./output_data/datasets_",p,".Rds"))

  # get step data
  steps.log <- datasets.all$step_count %>%
    select(step_count, dsource, timestamp, intervals.alt, dates, times)

  # calculate results
  source("./Rscripts/mod_steps.R") # calculate step counts by day
  steps.win <- pattern_steps(steps.watch %>% ungroup(), # counts steps by time windows
                             win.size = win.size)
}

# clear environment
remove(win.size, steps.log)
```

```r
# ----------------------------------------------
# MODULE: STEPS
#
# This module splits step data by source (watch or phone) then restructures it
# such that the cumulative count is over a daily cycle (24hrs) instead of
# between device reset/restart (uses the custom function "daily_steps"). A
# summary of daily totals is created merging the watch and phone data.
#
# ----------------------------------------------


# step count over day (restructure cumulative count) for each device:
steps.watch <- daily_steps(steps.log,"watch")
steps.phone <- daily_steps(steps.log,"phone")

# summary of daily total steps by device
steps.totals <- merge(x=steps.watch %>% summarise(total = max(stepcounter)),
                      y=steps.phone %>% summarise(total = max(stepcounter)),
                      by="dates", suffixes=c(".watch",".phone"),
                      all.x = TRUE, all.y = TRUE,
                      incomparables = NA)
```

Activity Features

Recognised activities data is used to detect bouts of the specified activities. The activity dataset is split into separate time series for each activity type (specified at setup above). Within each activity set, bouts are calculated as follows: if a reading is within 10 minutes of previous, assign to the same bout as previous, otherwise start new bout. Custom functions for written for bout detection are located in the script "jrt_activity". Inputs include: * activity log with timestamp, activity label (e.g. "still"), confidence * activities of interest * time window for bouts (default 10 minutes used here) Outputs include: * activity bouts, with activity type, bout number (chronological sequence), start and end time, number of readings, duration * summary per day giving the total number of bouts and cumulative durations for each activity type

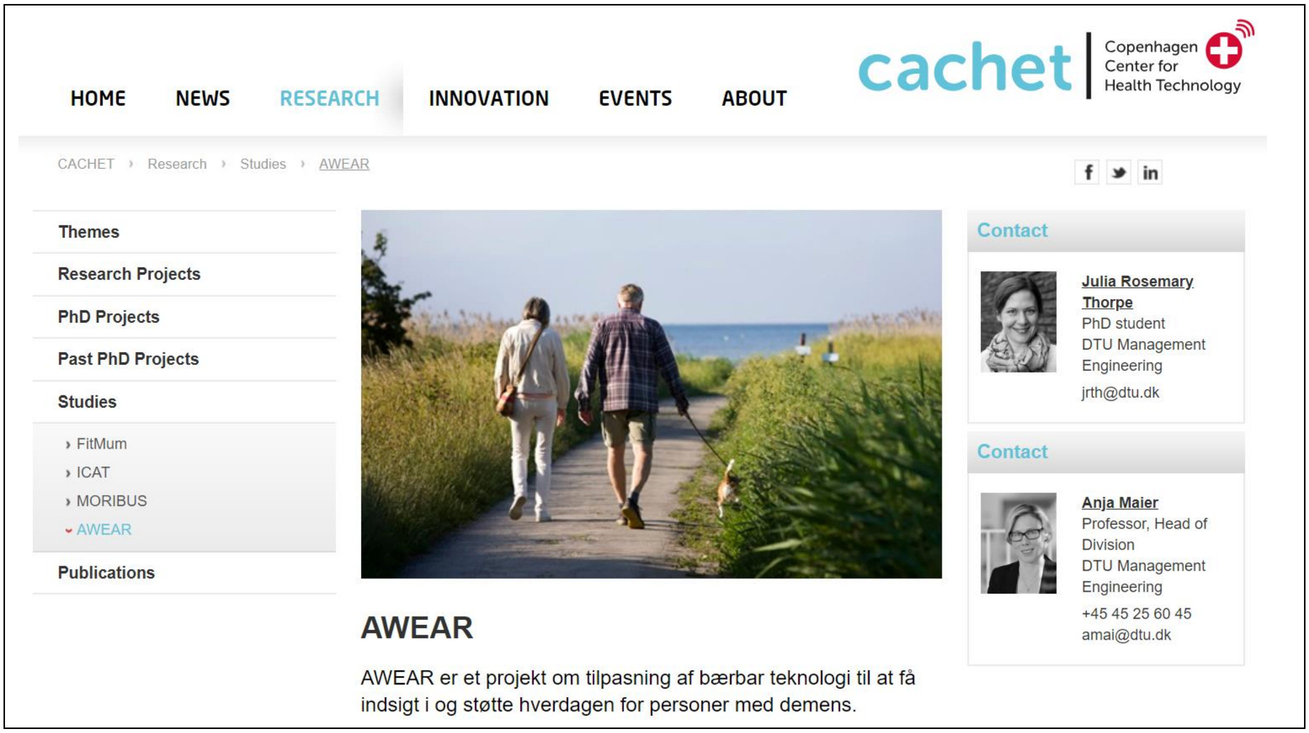
```r
for(p in p.codes){

  # unpack participant data
  P <- participants[[p]]
  list2env(P, .GlobalEnv); remove(P)
  d.study <-  as.numeric(round(difftime(d.stop, d.start, units = "days"))) # participation period
  datasets.all <-  readRDS(paste0("./output_data/datasets_", p, ".Rds"))

  # get activity data
  activity.log <- datasets.all$activity %>% filter(label %in% acts)

  # keep only the entries with max confidence for each timestamp (multiple max-confidence activities per timestamp possible)
  before <- nrow(activity.log)
  activity.log %<>%
    group_by(timestamp) %>% filter(confidence == max(confidence)) %>%
    ungroup() %>% as.data.frame()
  after <- nrow(activity.log)
  cat("Complete: activity data reduced by ", 100-(100*after/before), "% by keeping only the max confidence for each unique t
imestamp \n");

  # calculate bouts
  activity.bouts <- activity_bouts(activity.log, acts); remove(activity.log)
  activity.bouts %<>% filter(size>1)

  # summarise by day
  activity.bouts.pday <- activity.bouts %>% group_by(dates, activity) %>%
    summarise(total.time =  sum(duration), N = n()) %>%
    mutate(mean.duration = total.time/N)

}
```

```
## Complete: activity data reduced by  46.44255 % by keeping only the max confidence for
```

```r
# ACTIVITY BOUTS ----

activity_bouts <- function(activity.log, acts){
  # separate data into separate streams each with own difftime
  # split each stream into bouts using a time threshold

  activities_list = vector("list",length(acts))

  for(i in 1:length(acts)){
    bouts <- get_bouts(activity.log, acts[i])
    activities_list[[i]] <- bout_info(bouts)
    }

  activity.bouts <- do.call("rbind", activities_list)


  return(activity.bouts)
}

get_bouts <- function(df, A){

  # Extract data for specified activity and detect bouts
  act.bouts <- df %>% filter(label == A) %>% select(timestamp, label, confidence, dates, times) %>%
    mutate(dtime = c(0, difftime(tail(timestamp,-1), head(timestamp,-1), units = "mins"))) %>%
    mutate(split = ifelse(dtime > 10, 1, 0)) %>%
    group_by(dates) %>% mutate(bout = cumsum(split))

  return(act.bouts)
}

bout_info <- function(bouts){
  # Extract data for specified activity and detect bouts
  bout.info <- bouts %>% group_by(dates, bout) %>%
    summarize( activity = label[1],
               b.start = min(timestamp), b.end = max(timestamp),
               mean.conf = mean(confidence),
               size = n())

  # assign duration and end time to bouts of a single reading
  bout.info %<>% mutate(duration = ifelse(size > 1, difftime(b.end, b.start, units ="mins"), 5),
                        b.end = b.start + 60*duration)

  return(bout.info)
}
```

F. AWEAR Study: Information webpage

The AWEAR study refers to the feasibility study presented in section 5.2 and published in [20]. Information about the study was posted on the CACHET website (show below) as a resource for those interested in participating during recruitment, and for enrolled participants to refer to. The webpage is available at: http://www.webcitation.org/72sLx5D2t



Om vores projekt

I dette projekt vil vi undersøge, hvordan smart teknologi (mobiltelefoner og smarturer) kan anvendes til at støtte borgere med demens i deres hverdagsliv. Det kunne f.eks. være brug af digitale kalendere eller alarmer, der giver påmindelser om at udføre opgave, overholde aftaler eller kommunikere med familie og venner. Sådanne urer og telefoner har sensorer, der kan indsamle data om brugerens aktivitet og placering. Disse informationer kan bruges til at måle, hvor aktiv brugeren faktisk er, og hvor meget hun/han f.eks. går ud eller opholder sig i hjemmet. Den slags informationer kan bidrage med viden om aktivitetsniveau og om de aktivitetsmål, man selv har, faktisk indfries.

Projektets formål er at samle erfaringer med denne måde at bruge smartteknologier på, i samarbejde med borgere med demens og deres pårørende. Vi afprøver to teknologier, hhv. en smartphone (mobiltelefon) og et smartur. Vi anvender disse teknologier med tre overordnede formål:

· At vurdere, om det rent faktisk kan lade sig gøre at måle mobilitet og aktivitet via data fra telefoner og ures sensorer.

· At sammenligne sensor-baseret målinger med borgeres egen opfattelse af deres aktivitet og mobilitet.

· Samt at belyse brugernes egen oplevelse af barrierer og muligheder i forbindelse med brug af teknologierne.

Hvad skal jeg gøre?

Du får udleveret ur og telefon og tager det med hjem. Undersøgelsen udføres hjemmefra over 8 uger. I projektperioden vil vi også bede dig udfylde nogle skemaer og i korte møder og interviews.

Orienterings møde

Ved det første møde udfylder du nogle spørgeskemaer, der belyser hverdagsaktiviteter og livskvalitet i hverdagen. Din pårørende vil også blive bedt om at udfylde et skema om demenssygdommens betydning i hverdagen. På dette møde instrueres du også i, selv at formulere et aktivitetsmål, der opleves som meningsfuld og efterstræbelsesværdigt. Det kunne f.eks. være at blive mere selvstændig i relation til at tage sin medicin, eller komme mere ud til sociale arrangementer. En projektmedarbejder støtter dig gennem denne proces.

Udlevering af smart enheder

Derefter introduceres du til det ur og den mobiltelefon og instrueres i, hvordan den skal anvendes for at understøtte de mål du selv har formuleret.

- 8 ugers periode -

Du bruger ur og telefon med henblik på at opnå egne mål (f.eks. at huske aftaler/opgaver, kommunikation mm)

Data indsamles fra enheder om f.eks. aktivitet, placering, antallet af telefonopkald beskeder sendt/modtaget på smartphone mm.

Du udfylder spørgeskema (<1-minut) dagligt på smartphone, der belyser egen oplevelse

Ugentlige telefonopkald fra et medlem af projektgruppen sikre, at du er tryg ved at anvende teknologien og evt. tekniske problemer løses

Slutningsmøde

Der afsluttes med et kvalitativt interview og du og din pårørende udfylder de samme spørgeskemaer som ved projektets start.

Mere om udstyr

Du får udleveret en smartphone (mobiltelefon) samt et smartwatch ("smart-ur"). Ved modtagelse af enheder, får du vist hvordan de kan anvendes til at indtaste din aftale og påmindelser og evt. andre relevante funktioner.

I projektperioden må telefon og ur også bruges til alt muligt andet, du kunne tænke dig. Til dig der allerede har en mobil telefon eller en smartphone, gøre vi alt hvad vi kan for at opsætte projekt telefon med de sammen funktioner, som du plejer bruge (f.eks. kontakteliste, applikationer osv.).

I projektet anvendes en Google Nexus 5 smartphone, et Sony Smartwatch 3 smartwatch, og forskellige applikationer inkl. Google Kalendar og Keep.

Smartphone: Google Nexus 5

Smartwatch: Sony Smartwatch

Hvem kan deltage?

Projektet henvender sig til borgere, som har fået konstateret demens i mild eller moderat form. For at deltage, behøver man ikke have erfaring med brug af smart teknologi, kun interesse for at anvende smartteknologier i hverdagen. Det er en forudsætning for deltagelse, at man har en partner/pårørende, som man bor sammen med.

Hvem kan få oplysninger?

Dit navn eller identitet vil ikke fremgå eller kunne identificeres i rapporter eller publikationer, som produceres af projektet. Hvis du ønsker det, kan du få adgang til dine egne data og undersøgelsesresultater. Resultaterne fra projektet vil blive søgt publiceret i videnskabelige tidsskrifter.

Hvordan håndteres sikkerhed?

Alle data som vi indsamler på telefonen sendes og opbevares krypteret så uvedkommende ikke kan få adgang til dem. Data opbevares på en server i på Danmarks Tekniske Universitet, som er underlagt EU's persondatadirektiv.

Informeret samtykke

Før du går i gang med studiet skal du sammen med en forsker gennemgår denne deltager information og underskrive et informeret samtykke.

Kontaktoplysninger

For information om praktiske detaljer omkring møde og interviews, kan du kontakte projekt stud.psych. Maria Özden på telefon: 61 65 46 87

For tekniske spørgsmål og rådgivning, kan du kontakte tekniske assistent Luna Hansen på telefon: 61 65 46 43 For generelt information om projektet, kan du kontakte forsker Julia Thorpe på mail (jrth@dtu.dk) eller telefon: 30 11 33 32

Projektledelse

Birgitte Hysse Forchhammer Ledende neuropsykolog Rigshospitalet-Glostrup

Anja Maier Professor of Engineering Systems DTU Management Engineering

Updated by Björgvin Hjartarson on 22 August 2018

COPENHAGEN CENTER FOR HEALTH TECHNOLOGY

DTU Technical University of Denmark

UNIVERSITY OF COPENHAGEN

CITY OF COPENHAGEN

REGION H The Capital Region of Denmark

The Copenhagen Center for Health Technology **[cachet]** is a strategic **partnership** between the Capital Health Region of Denmark, the City of Copenhagen, the University of Copenhagen, and the Technical University of Denmark. The strategic **objective** is to strengthen interdisciplinary and cross-organizational research and development within personalized health technology.

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G. AWEAR Study: User manual for operating study phones

Participants in the AWEAR study (section 5.2, published in [20]) were provided with a user manual to guide basic operation of the smartphone and smartwatch provided in the case studies, and is shown below.

Revideret 13.03.2018

Brugsvejledning til udleveret smartteknologi

Forord 2

Denne brugervejledning skal hjælpe med at anvende den udleverede smart-teknologi. Udstyret består af en smartphone samt et smartur og vejledningen er derfor opdelt i brugen for hver af de to enheder. Vejledningen vil primært forklare brugen af udvalgte væsentlige funktioner, som kan anvendes som en støtte i hverdagslivet, og vil altså ikke forklare brugen af samtlige funktioner i enhederne.

Ved behov for øvrig teknisk vejledning kan projektets tekniske assistent, Luna Hansen tillige kontaktes på telefon: 61 65 46 43

Indholdsfortegnelse 3

Indholdsfortegnelse ... 3
Kom godt i gang ... 4
Overblik over telefonens opbygning ... 4
Overblik over urets opbygning ... 5
Brug af telefon ... 6
Sådan låses telefonen op ... 6
Indhold på telefonens hjemmeskærm ... 7
Brug af opkaldsfunktion ... 8
Brug af kalenderfunktion ... 9
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Brug af sms-funktion - Skrive og sende sms ... 12
Brug af note funktionen; Google Keep ... 13
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Anvendelse af berøringsskærmen ... 15
Aktivitets Spørgsmål ... 16
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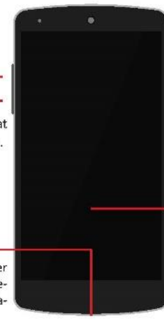
Kom godt i gang 4

Overblik over telefonens opbygning

Telefonens forside



Lydstyrke op

Lydstyrke ned

Tryk på disse knapper for at justere telefonens lydstyrke.

Tænd/sluk-knap

Ved kort tryk på denne knap tændes og slukkes telefonens skærm, mens telefonen forbliver tændt. Telefonen slukkes helt ved at trykke på knappen over længere tid.

Berøringsskærm

Skærmen kan registrere når der trykkes på den, som udnyttes til at styre telefonen.

Opladerindgang

I bunden af telefonen sidder opladerstikket som opladeren skal tilsluttes for at oplade telefonen.

Telefonens bagside

Kamera

På bagsiden sidder telefonens kameralinse som gør at telefonen kan bruges som foto- samt video-kamera.

5

Overblik over urets opbygning

Urets forside

Berøringsskærm

Skærmen kan registrere når der trykkes på den, som udnyttes til at styre uret.

Urets bagside

Tænd/sluk-knap

Tryk kortvarigt på denne knap for at vække eller nedtone skærmen.

Dæksel til opladerindgang

Uret oplades ved at åbne gummidækslet, og tilslutte opladeren til stikket gemt under dækslet.

Brug af telefon 6

Sådan låses telefonen op

1. Tryk kort på tænd/sluk knappen for at tænde skærmen.

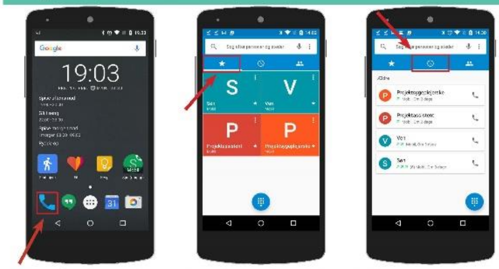
2. Stryg fingeren op af skærmen for at låse telefonen op.

7

Indhold på telefonens hjemmeskærm

8

Brug af opkaldsfunktion



1. Tryk på telefonrøret for at starte opkaldsfunktionen.

2. Ved markering af stjernen, vises kontakter markerede som favoritter. Et tryk på en favorit starter opkald.

3. Ved markering af uret vises en liste over seneste opkald.

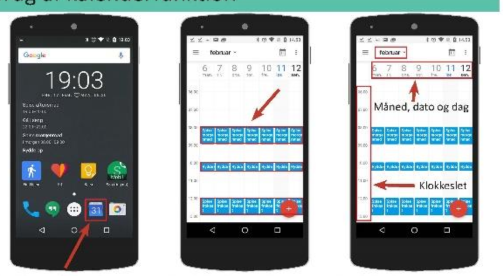
4. Ved en streg under de to personer vises en liste over alle kontakter.

5. Ved tryk i denne boks kan der søges blandt alle kontakter.

6. Ved tryk på dette ikon kan der tastes et telefonnummer ind manuelt.

9

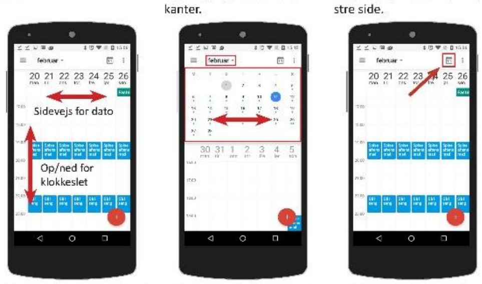
Brug af kalenderfunktion



1. Tryk på kalenderikonet for at starte kalenderfunktionen.

2. I kalenderen vises planlagte begivenheder for en uge af gangen som små firkanter.

3. Begivenhederne vises ud fra måned, dato og dag i toppen, og klokkeslet i venstre side.



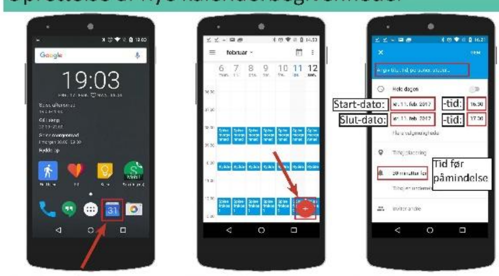
4. For at vise andre tider i kalenderen stryges en finger op/ned for klokkeslet, eller sidevejs for dato.

5. Ved tryk på den viste måned, kan måneden skiftes ved at stryge en finger sidevejs i det viste felt.

6. Tryk på dette ikon for at komme til dags dato.

10

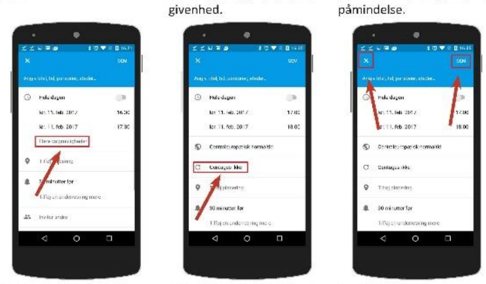
Oprettelse af nye kalenderbegivenheder



1. Tryk på kalenderikonet for at starte kalenderfunktionen.

2. Tryk på det røde ikon med et plus for at tilføje til kalenderen og vælg herefter begivenhed.

3. Udfyld titel, datoer og tidspunkter for begivenheden. Eventuelt tilpas tid for påmindelse.



4. Er begivenheden tilbagevendende, og skal gentages tryk på 'Flere valgmuligheder'.

5. Tryk hvor der står 'Gentages ikke' for at slå gentagelse til ved at angive interval.

6. Begivenheden gemmes ved at trykke på 'GEM', eller kaseres ved at trykke på krydset.

11
Brug af sms-funktion - Vælge modtager

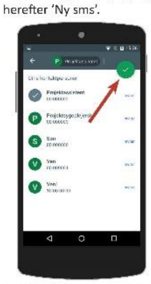
1. Tryk på det grønne sms-ikon for at starte sms-funktionen, Hangouts.

2. Har du skrevet sms'er med modtageren før, kan du vælge denne på listen over samtaler.

3. For at sende en sms til en ny modtager, tryk på ikonet med det grønne plus, og herefter 'Ny sms'.

4. Vælg herefter modtager fra listen af navne, ved at trykke på det. Skriv evt. navnet for at filtrere listen.

5. Valgte modtagere vises i toppen. For at fjerne en modtager, tryk på navnet og herefter på krydset.

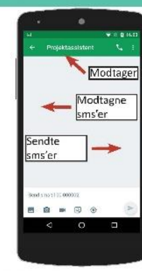


6. Tryk på det grønne 'hak' når korrekt modtager er valgt.

12
Brug af sms-funktion - Skrive og sende sms

1. Tryk på det grønne sms-ikon for at starte sms-funktionen, Hangouts.

2. Følg vejledningen, 'Valg af modtager' til at vælge korrekt modtager.



3. Ved valgt modtager, vises hele samtalen, haft over sms, med denne.

4. Tryk på tekstfeltet hvor der står 'send sms til' for at få tasteturet frem, og mulighed for at skrive sms.

5. Brug herefter tasteturet til at skrive sms, som vil kunne læses i tekstfeltet.

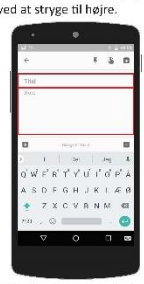
6. Tryk på denne pil for at sende sms.

13
Brug af notefunktionen; Google Keep

1. Notefunktionen kan tilgås direkte fra hjemmeskærmen, men anvendes lettest ved at stryge til højre.

2. Notefunktionen vises i det markerede område, hvor gemte noter vil vises

3. Der kan oprettes fem forskellige typer noter, som vælges ved tryk på et af de fem ikoner markeret.



4. Ved valg af 'note', gives der mulighed for at angive en titel for noten, og noten selv.

5. Tekst

6. Tekst

Brug af smart-ur 15
Anvendelse af berøringsskærmen

Stryg

Stryg op	• Vis flere notifikationer, hvis de er tilgængelige. • Gå nedad i en liste med valgmuligheder.
Stryg ned	• Se tidligere kort, hvis de ikke er blevet afvist. • Gå opad i en liste mod valgmuligheder.
Stryg til venstre	• Se flere oplysninger og handlinger, hvis de er tilgængelige.
Stryg til højre	• Afvis en notifikation, eller luk en menu.

Tryk

Tryk	• Åbn eller vælg et element.

Nedtoning og vækning af skærm

Sådan vækker du skærmen

Foretag én af følgende handlinger:
- Tryk på skærmen
- Tap på skærmen, eller tryk kortvarigt på tænd/sluk-tasten.

Sådan nedtoner du skærmen manuelt

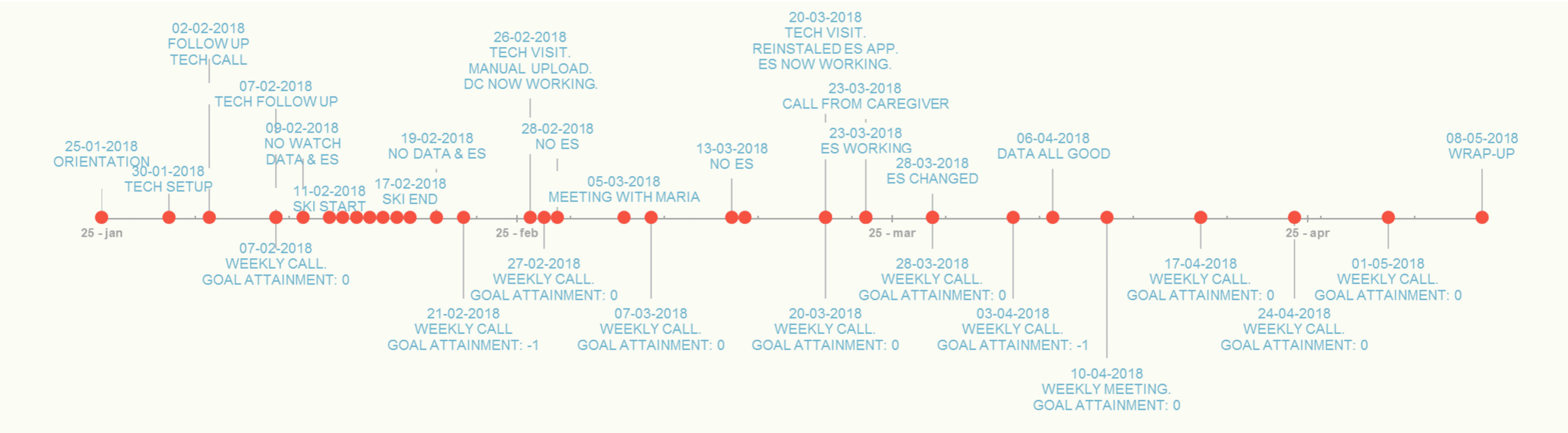
Foretag én af følgende handlinger:
- Anbring din hånd over skærmen, indtil den vibrerer.
- Tryk kortvarigt på tænd/sluk-tasten.


Aktivitets Spørgsmål 16
Åben og besvar daglige spørgsmål
12.13
1. Følgende besked vises på dine låseskærm. Lås først skærmen op ved at stryge op med fingeren.
2. Stryg ned med din finger fra toppen af skærmen.
3. Tryk på bjælken hvor der står "Hurtigt spørgsmål til dig". En af de følgende spørgsmål vil nu åbnes.
4. Tryk på det svar du ønsker at angive. Tryk herefter "Svar". Dette spørgsmål får du 3 gange dagligt.
5. Dette spørgsmål får du 1 gang dagligt.
6. Dette spørgsmål får du 1 gang dagligt.

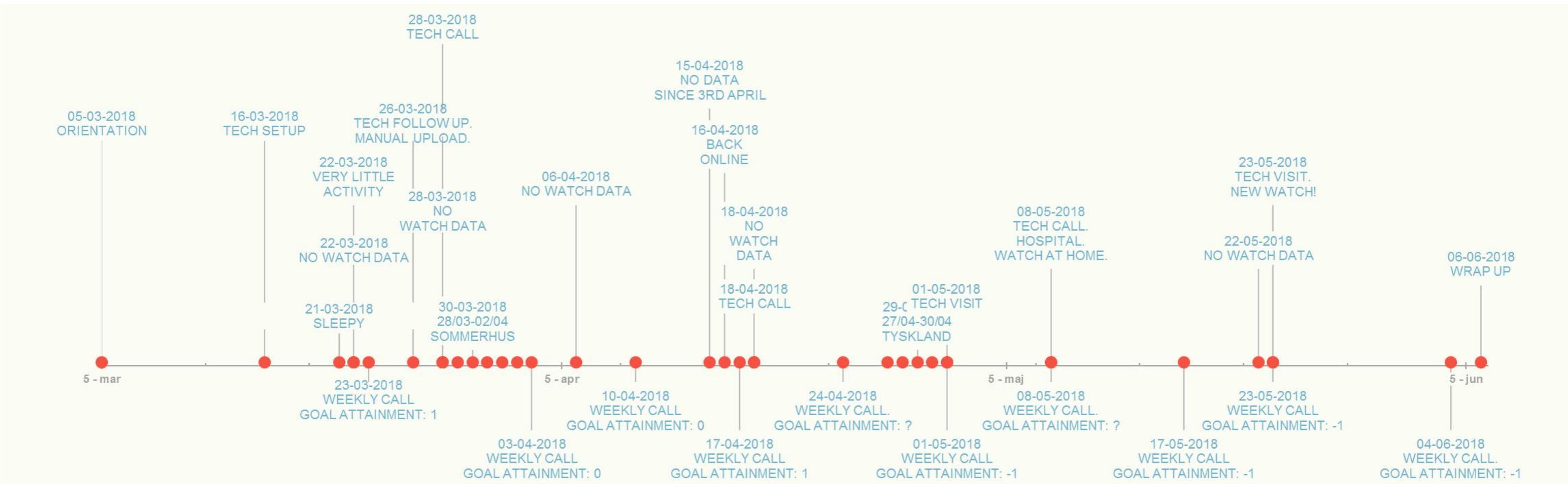
H. AWEAR Study: Participant timelines

Interactions with participants in the AWEAR case studies (section 5.2, published in [20]) included both those scheduled according to the study protocol (e.g. weekly phone calls to evaluate goal attainment) and ad-hoc interactions e.g. for technical support. All documented interactions were gathered by participant to provide an overview of the case along a timeline, which are illustrated in the following pages for each of the six study participants.

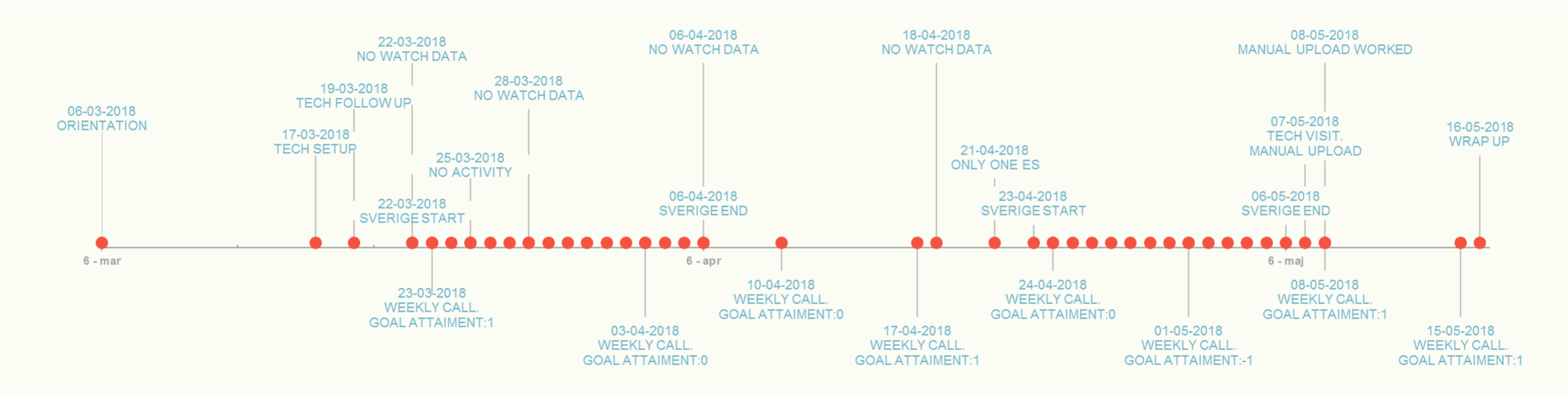
Participant 1



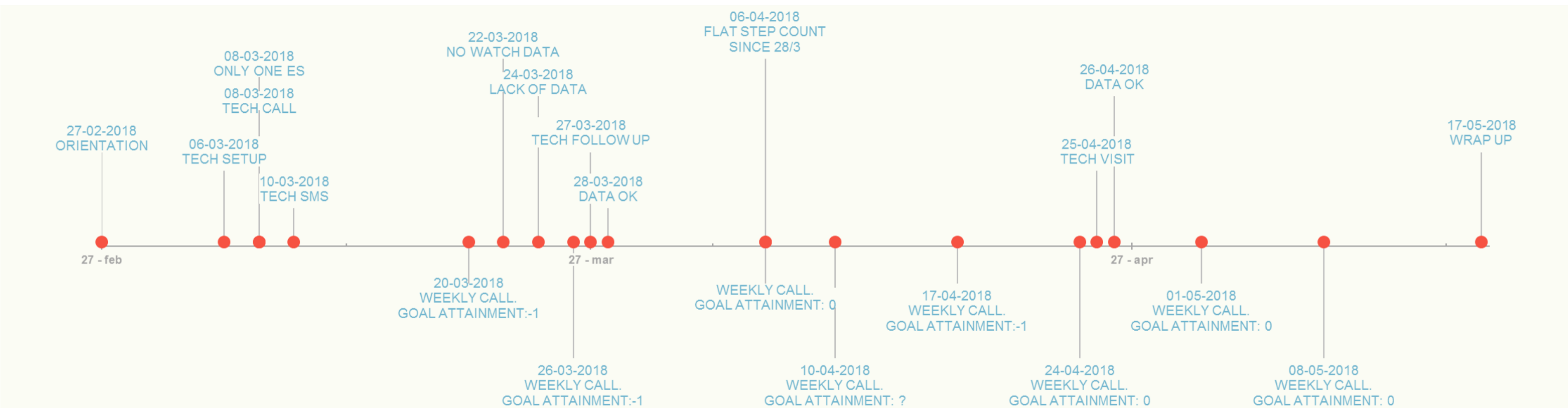
Participant 2



Participant 3

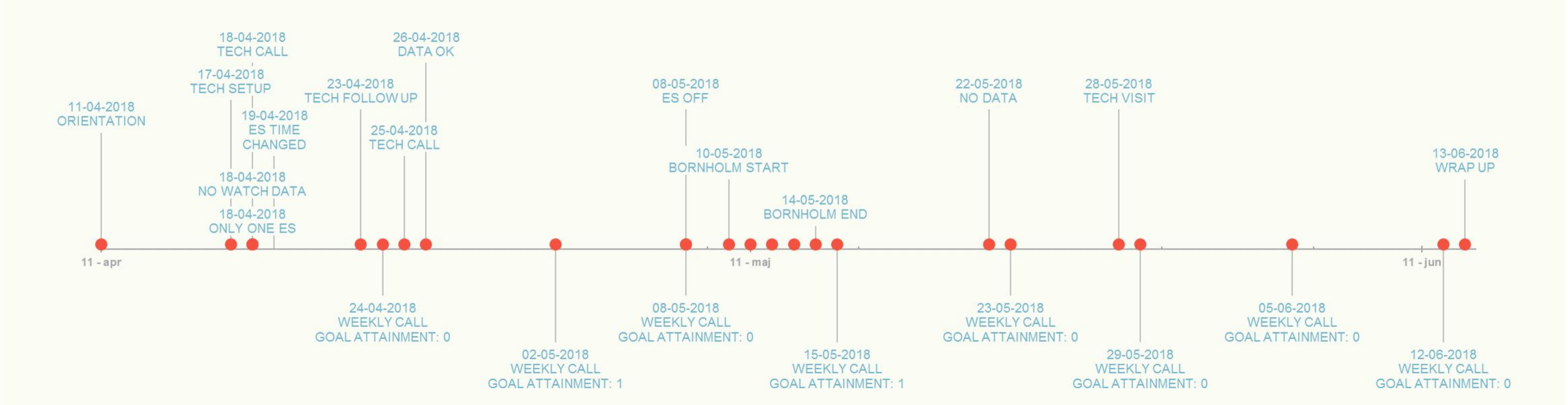


Participant 4



Participant 5

Participant 6



I. AWEAR Study: Data checker notebook

An R notebook was created to generate reports for internal use among the research team to evaluate incoming data during the AWEAR case studies (section 5.2, published in [20]). These were used to make sure that data was being generated and uploaded from both the smartphone and smartwatch, to visually inspect the data to make sure it looked as might be expected. An example report is shown below using dummy data so as to ensure anonymity among study participants.

AWEAR Studies: Data Checker

Code ▾

Julia Thorpe

This notebook was written for the AWEAR Case Studies as part of a PhD project on *Engineering Systems Design in Healthcare* at the Engineering Systems Division, DTU Management, in collaboration with Rigshospitalet-Glostrup.

The purpose of this notebook is to provide regular reports on the data being recorded from study participants, to check that it is being recorded and looks as expected. The R script imports, tests and plots data from a specified participant and timeframe, as shown in the code and output below.

Report subject and period:

```
This report is for user  julia for the time period from  2018-03-17  to  2018-03-24
```

Import and restructure data:

Overview of available csv files and their current use status:

File	Description	Status
"activity.csv"	coded activity types	in use
"battery.csv"	charging log	in use
"bluetooth.csv"	-	not in use
"calllog.csv"	log of phonecalls	not in use
"experience_sampling.csv"	answers to daily self-reports	in use
"hardware_info.csv"	-	not in use
"location.csv"	GPS data from watch and phone	in use
"screen.csv"	screen on/off transitions (phone)	in use
"sms.csv"	sms log	not in use
"step_count.csv"	step counts from watch and phone	in use
"wearable.csv"	-	no longer in use
"wifi.csv"	-	not in use

The output below confirms which files have been imported, followed by processing steps.

```
activity file imported
battery file imported
calllog file imported
experience_sampling file imported
location file imported
screen file imported
sms file imported
step_count file imported

 ***
 Processing file containing:  activity confidence

Complete: Data extracted for specified user
Complete: Data extracted for period of interest
Complete: funf_version converted to dsource column indicating whether reading is from phone or watch
Complete: column 'label' created describing activity based on activity code
```

```
Complete: column 'label' created describing activity based on activity code
Complete: activity data reduced from  3716  to  1884  rows by keeping only the max-confidence activities for each unique tim
estamp

 ***
 Processing file containing:  plugged status level

Complete: Data extracted for specified user
Complete: Data extracted for period of interest
Complete: funf_version converted to dsource column indicating whether reading is from phone or watch
Complete: column 'mode' created describing charging status based on 'plugged' variable

 ***
 Processing file containing:  name number type duration

User ID is not in dataset, returning NULL
```

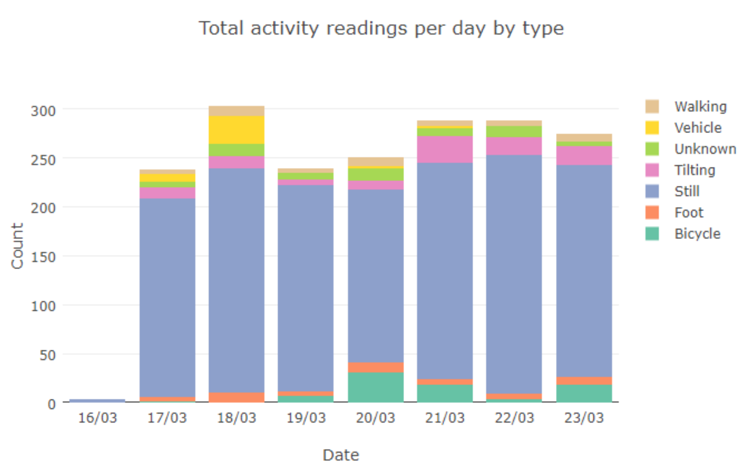
```
 ***
 Processing file containing:  screen_on

Complete: Data extracted for specified user
Complete: Data extracted for period of interest
Complete: funf_version converted to dsource column indicating whether reading is from phone or watch

 ***
 Processing file containing:  address body type read

User ID is not in dataset, returning NULL

 ***
 Processing file containing:  step_count

Complete: Data extracted for specified user
Complete: Data extracted for period of interest
Complete: funf_version converted to dsource column indicating whether reading is from phone or watch
```

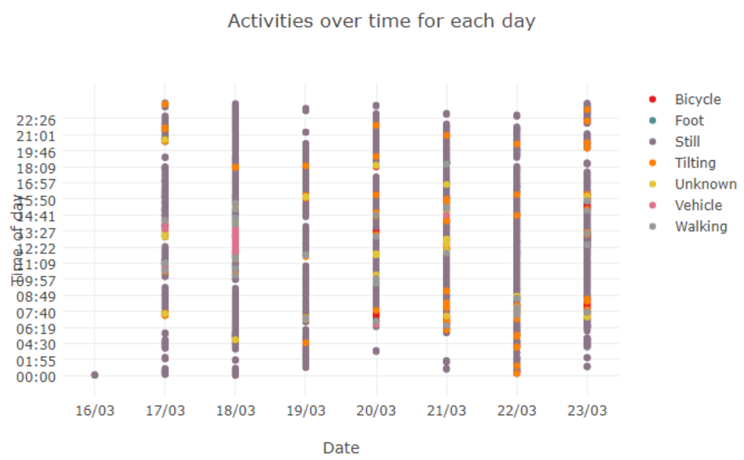
Quality check: data source

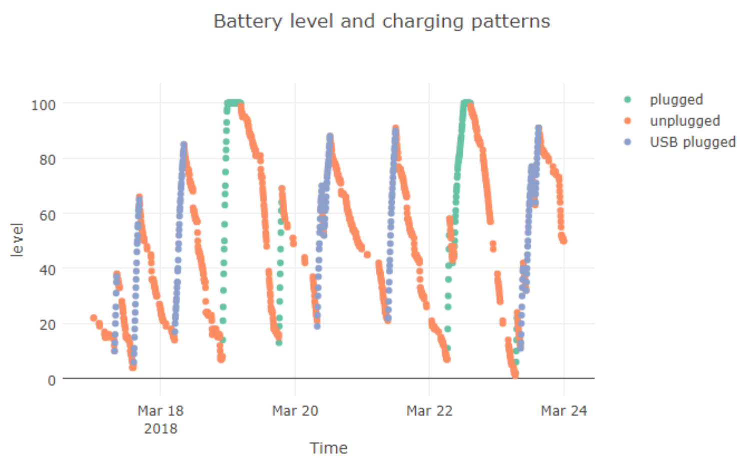
Check whether data coming from watch, phone or both (also gives date of last reading).

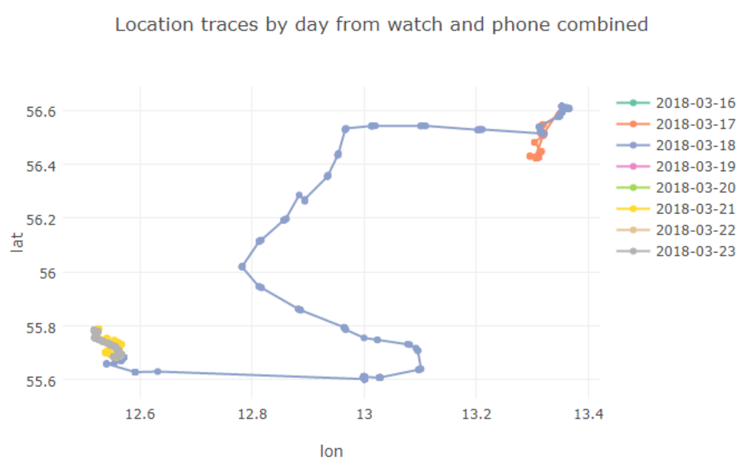
```
Data in  activity comes from  phone
Last reading in activity is on [1] "2018-03-23 23:56:48 CET"

Data in  battery comes from  phone
Last reading in battery is on [1] "2018-03-23 23:56:48 CET"

Data in  location comes from  phone
Last reading in location is on [1] "2018-03-23 23:57:15 CET"

Data in  screen comes from  phone
Last reading in screen is on [1] "2018-03-23 23:16:02 CET"

Data in  step_count comes from  phone watch
Last reading in step_count is on [1] "2018-03-23 23:56:48 CET"
```

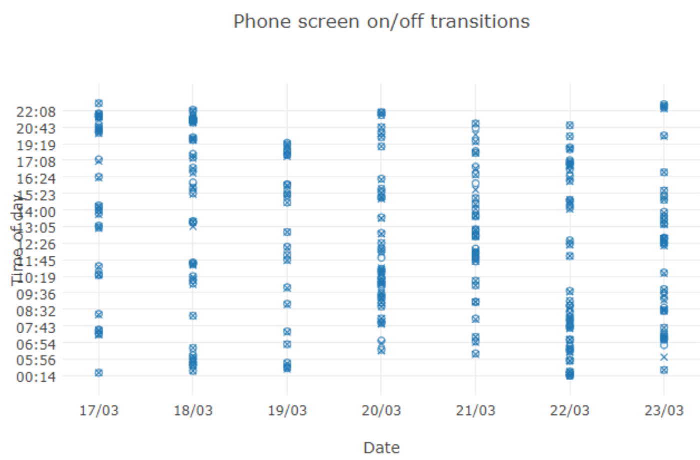
Visualise data:

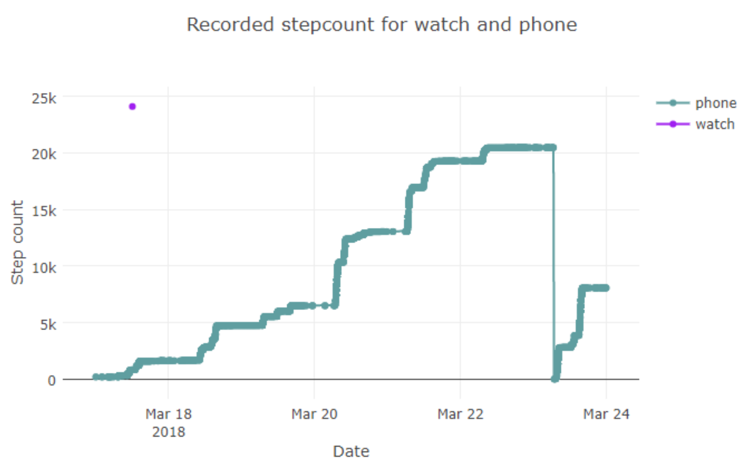



Activities over time for each day
Time of day
22:26
21:01
19:46
18:09
16:57
15:50
14:41
13:27
12:22
11:09
09:57
08:49
07:40
06:19
04:30
01:55
00:00
16/03
17/03
18/03
19/03
20/03
21/03
22/03
23/03
Date
Bicycle
Foot
Still
Tilting
Unknown
Vehicle
Walking


Battery level and charging patterns
level
100
80
60
40
20
0
Mar 18
2018
Mar 20
Mar 22
Mar 24
Time
plugged
unplugged
USB plugged


Location traces by day from watch and phone combined
lat
56.6
56.4
56.2
56
55.8
55.6
12.6
12.8
13
13.2
13.4
lon
2018-03-16
2018-03-17
2018-03-18
2018-03-19
2018-03-20
2018-03-21
2018-03-22
2018-03-23





Excerpt from R notebook created to generate reports for internal use among the research team to evaluate incoming data during the AWEAR case studies (section 5.2, published in [20]). The notebook is part of the thesis project at DTU and in collaboration with Rigshospitalet-Glostrup, entitled 'Engineering systems design in healthcare: Smart mobile and wearable technology for support and monitoring in dementia rehabilitation.