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Dementia Ambient Care: Multi-Sensing Monitoring for Intelligent Remote Management and Decision Support

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Abstract **(for dissemination)**	This deliverable if the first output from task 2.5. It presents a methodology for assessing and measuring the impact that Dem@Care has on the lives of the many stakeholders involved in the care of people with dementia, the socio-economic benefits, and the expected scientific impact on the clinical and technical state-of-the-art. It is based on an understanding of current care management practices, the role of ICT solutions in dementia are, and on the evaluation of the first pilot.

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Executive Summary

This deliverable presents a methodology for assessing and measuring the impact that Dem@Care has on the lives of the many stakeholders involved in the care of people with dementia, the socio-economic benefits, and the expected scientific impact on the clinical and technical state-of-the-art. It is based on an understanding of current care management practices, the role of ICT solutions in dementia are, and on the evaluation of the first pilot.

The goal of the Dem@Care project is to develop a closed-loop management solution for people with early or mild-stage dementia through multi-parametric remote monitoring and individual-tailored analysis of physiological, behavioural and lifestyle measurements. This solution will be tailored for three specific operational scenarios: the lab (Dem@Lab), the nursing home (Dem@Nursing), and the home (Dem@Home). Although these three clinical scenarios are distinctly different, the components and combinations of components are used in similar ways in each setting, which facilitates a single impact evaluation strategy.

Dem@Care is expected to positively affect people with dementia by helping to maintain their independence, facilitating a sense of improvement in five key domains (sleep, physical activity, social interaction, activities of daily living, and mood), and by helping to ensure their security and safety. Achieving these outcomes is expected to improve the subjective quality of life of these individuals, and of those who care for them, and it should help maintain their integration in society. Clinicians and formal care staff will benefit from improved assessment and diagnostic procedures, and more timely identification of functional, behavioural, and emotional pattern changes. The successful attainment of these personal impacts will, over time, lead to socio-economic benefits such as a reduction in healthcare costs, improved personal finances for informal carers, and more socially inclusive dementia-aware and dementia-friendly societies. Finally, the Dem@Care project is expected to advance the technical, clinical, and ethical state-of-the-art through the innovation application of ICT solutions to dementia care.

The personal and societal impact assessment strategy will not only measure the actual outcomes of the Dem@Care project, but also the perceived outcomes for each of the stakeholder groups. As a result, a mixed methods approach will be used, along with a variety of objective and subjective measurement tools. Assessment of quality of life, well-being, and sense of improvement in the five domains of interest and in general, will be central to the evaluation of personal impact. As will the acceptability and usability of the system for the various end-user groups. Although it will be difficult to evaluate the longer-term societal outcomes, acceptability to decision- and policy-makers, and user perceptions of cost consequences and social inclusion will be explored. The accuracy of the sensor driven analysis, the associated provision of new software solutions, the debate and resolution of concomitant ethical issues, and the dissemination of results to a wide-ranging stakeholder audience, will provide the basis for the evaluation of scientific state-of-the-art impact.

Finally, a brief overview of the results of the first Dem@Care pilot evaluation illustrate progress towards these objectives and highlight a range of key issues that will require resolution in order to ensure that the expected Dem@Care impacts are realised.

Abbreviations and Acronyms

@Home	First pilot in the home environment in Ireland
@Lab	First pilot in the lab environment in France
@NH	First pilot in the nursing home environment in Sweden
ACT	Activities of Daily Living
BPSD	Behavioural and Psychological Symptoms of Dementia
Dem@Home	@Home deployment of the Dem@Care system
Dem@Lab	@Lab deployment of the Dem@Care system
Dem@Nursing	@Nursing Home deployment of the Dem@Care system
ICT	Information and Computer Technology
MMSE	Mini Mental State Exam
MT	Medium-term
p.p.	Percentage points
LT	Long-term
PwD	Person with dementia
QoL	Quality of Life
SOA	State-of-the-art
ST	Short-term

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1   Introduction

The age structure of the EU population is projected to dramatically change in coming decades; the overall size of the population is projected to be slightly larger in 50 years time, but much older than it is now [1]. The EU population is expected to increase from 502 million in 2010 to a peak of 526 million by 2040 and then decline to 517 million by 2060. The most numerous age cohorts in 2010 are around 40 years old for men and women, but persons aged 65 or more are projected to account for an increasing share of the population, almost doubling in size from 87.5 million in 2010 to 152.6 million in 2060 (rising from 17% to 30% of the population). The number of older people (aged 80 years and above) is projected to increase by even more, almost tripling from 23.7 million in 2010 to 62.4 million in 2060 (rising from 5% to 12% of the population). As a result, the old-age dependency ratio (people aged 65 or above relative to those aged 15-64) is projected to increase from 26% to 52.5% in the EU over this time.

Frailty and disability rise sharply at older ages, causing older people to become more dependent on others [2]. Dependency, in this instance, refers to difficulties in performing at least one activity of daily living (ADL), and it has been shown to be an important determinant of increased need and long-term care expenditure particularly when longevity is not accompanied by a corresponding improvement or stabilisation in the quality of life of the individual [3]. Although the overall health of the EU population is likely to continue to improve over this time, higher levels of some disabling conditions (e.g. dementia), go along with decreasing rates of prevalence of others (e.g. cardiovascular and chronic respiratory diseases) [4]. An ageing population is therefore expected to have a strong upward impact on age-related EU public expenditure, which is expected to increase by 4.1 percentage points (p.p.) of GDP by 2060. Most of the projected increase is expected to be on pensions (+1.5 p.p. of GDP), long-term care (+1.5 p.p. of GDP) and health care (+1.1 p.p. of GDP), with public spending on long-term care expected to double to 3.4% of GDP by 2060 [5].

Research has shown that dementia and cognitive impairment, along with other neurodegenerative diseases, are by far and away the leading chronic disease contributors to dependence, and, in high income countries, to transitions from independent or supported living in the community, into care homes [5]. Today, more 9.9 million people in Europe, are living with dementia [6] accounting for over 28% of the total number of people with dementia worldwide. Around half of all people with dementia (PwD) need personal care; the others will develop such needs over time. Dementia is thus significantly affecting every health system in the world. The total estimated costs of dementia in 2010 were USD 604 billion worldwide [7] and USD 135.04 billion in the EU [6].

Health care policies in many countries aim to enable PwD to live in their own homes as long as possible, and one of the associated benefits is an expectation that the financial burden of the disease will be reduced [8], but it places a higher demand on formal care services and informal care in the middle phase of dementia. Two thirds of PwD are living in the community, either alone or with a family member. Unpaid family carers provide significant care and support, and it is estimated that over 70% of the PwD in Europe are currently receiving unpaid care [9]. But informal carers can experience high levels of stress, depression, social isolation and physical health problems [10], and as the disease progresses, the burden of informal care increases. In addition, the increasing number of people living alone, increasing labour participation of women who still provide the majority of informal

caregivers, and falling birth rates are likely to reduce the caregiving potential within families [11, 12] and increase the pressure on formal and long-term care facilities. This highlights the importance of using formal home-based services to support the PwD and also their families.

The overall goal of the Dem@Care project is to provide an integrated remote care and management solution for people with dementia. Task 2.5 will assess and measure the impact that Dem@Care has on the lives of the many stakeholders involved in the care of PwD. This includes measuring how Dem@Care can enhance the quality of life and the well-being of people with dementia and their caregivers, and this evaluation follows on from the pilot trials in Sweden, France, and Ireland (T8.1, T8.2, and T8.3 respectively). Aspects to be assessed include detecting and either reducing or eliminating factors that increase stress and/or risks, such as timely diagnosis and cognitive support, measures of increased independence, and feelings of improved psychological well-being. Also included are the benefits of maintaining integration in society and thus improving social skills and the ability to maintain these skills. The prolongation of the stay of PwD in their homes will be an important measure of Dem@Care's success. In addition to the personal impact on PwD and their caregivers, the impact of Dem@Care on clinicians and formal care staff will be assessed, along with the broader socio-economic impacts for health and social care provision, financing, and the furthering of clinical, technical, and ethical, state-of-the-art research.

This initial impact report is the first deliverable (D2.7) from Task 2.5. The report describes the goals and expected outcomes of the Dem@Care project, and it presents a strategy for the evaluation of these outcomes across the three pilot settings. It is organized as follows. In Section 2, we describe the current clinical and technical environments from which the Dem@care system was conceived and built, and which essentially forms the baseline from which the impact of the system will be measured. In Section 3, we discuss the main elements of an impact assessment, the key stakeholders involved in this Dem@Care evaluation, and then we present the personal impact assessment plans for the person with dementia, their informal carers, and for clinicians and formal, the societal impact assessment plans which have been broadly categorised as social or economic outcomes, and the scientific "state-of-the-art" (SOA) impact assessment plans across clinical, technical, and ethical domains. In each case, the expected outcomes, the timeframe, the measurement tools, and the contributing activities have been identified. The key findings from the first pilot evaluation (D8.3) are summarised in Section 4. We discuss these findings in terms of what they tell us about the current impact of the Dem@Care system, and the resulting issues and recommendations for future evaluations. Finally, our conclusions are presented in Section 5.

2 The Current Dementia Care Environment

2.1 Providing care for mild to moderate dementia

Dementias are progressive, with a gradual increase in loss of cognitive and functional capacities. Two thirds of PwD are living in the community, either alone or with a family member. In the early stages, people can often continue to perform many tasks independently. As the condition progresses, PwD in a moderate disease stage will need increasing amounts of care and support, as they start to lose the ability to perform everyday tasks. Unpaid family carers provide significant care and support; over 70% of the PwD in Europe are currently receiving unpaid care [9]. Research in 2007 estimated that the total cost of dementia across 15 western European countries was 189 billion Euros, most of which was attributable to the 11.9 billion hours of unpaid care from family and friends (5).

Spouses comprise the largest proportion of informal caregivers, followed by children and children in-law, mostly female. The typical profile of a dementia caregiver is a middle-aged or older female child or spouse of the person with dementia, although informal carers are often partners of advanced age who themselves face health and social care challenges. In the US, at least 60% of unpaid caregivers are wives, daughters, daughters-in-law, granddaughters, and other female relatives, although male caregivers are becoming more frequent [8]. In 2008 men made up 40% of family caregivers in the US, an increase of 21 % from a 1996 study by the Alzheimer's Association. In the UK, men aged over 75 are more likely than women to be caring for their spouse. As a result, family caregivers of PwD are critical to the quality of life of the care recipients, however, the impact of providing informal care on the lives and health of informal caregivers has been shown to be substantial. These impacts, though sometimes positive, are generally negative, with high rates of burden and psychological morbidity as well as social isolation, physical ill health, and financial hardship [10, 13, 14].

Family caregivers may be motivated to provide care for several reasons: a sense of love or reciprocity, spiritual fulfilment, a sense of duty, guilt, social pressures, or in rare instances, greed. Caregivers who are motivated by a sense of duty, guilt, or social and cultural norms are more likely to resent their role and suffer greater psychological distress than caregivers with more positive motivations. Caregivers who identify more beneficial components of their role experience less burden, better health and relationships, and greater social support [15]; between 55% and 90% of caregivers experienced positive experiences such as enjoying togetherness, sharing activities, feeling a reciprocal bond, spiritual and personal growth, increased faith, and feelings of accomplishments and mastery. Gender, age, education, and ethnicity can also influence the way caregivers view their role. Feeling more positively towards care giving has been associated with lower educational level, greater social resources, satisfaction with social participation and better physical health status, being non-Caucasian, and being older [15].

Health care policies in many countries aim to enable PwD to live in their own homes for as long as possible, so that they can maintain independence, dignity, and a sense of well-being for as long as possible. They do so by striving to develop better home-based and community services and reduce institutionalisation [16]. Unfortunately, research has revealed that PwD and their carers are not receiving services of the type and quality that they need, and that they experience much difficulty accessing and working with community care services, even when

having a diagnosis of dementia [15, 17]. This can put increasing pressure on PwD and their carers which might lead to admission to a residential home simply because the appropriate support is not in place [18]. This highlights the importance of developing formal home-based services to support PwD and their families.

2.2   The role of ICT solutions in dementia care

ICT solutions have the potential to facilitate daily life for dependent and disabled people, including those with a diagnosis of dementia [19]. Various research projects have explored the use of sensing technology for remote monitoring, environment monitoring and physiological sensing for people with dementia over the past two decades. Examples of technologies for assisted living are provided in Chapman [20] who discusses e.g. automatic shut-off devices for cookers, alarms for remote care facilities, alert devices for resident carers, time orientation devices and bed occupation sensors. In the overview paper by Stefanov et al. [21], the building blocks of a 'smart house', a house including devices that have automatic functions and systems that can be remotely controlled by the user, are analyse. The following categories are distinguished: assistive devices (e.g. movement assistance), health monitoring devices (e.g. pulse rate, blood pressure, body temperature and posture monitoring), systems for information exchange, and leisure devices. One of the most important requirements given for the sensors by Stefanov et al. [21] is that they should be non-invasive and wearable. Examples of non-invasive and wearable sensors that are provided include pulse oximetry, electrocardiography (ECG) chest band, ECG in textile (pillow during sleep), acoustic monitoring of the heart, breath, snoring, wheezing, radar for detecting heart rate and pulmonary activity, multimodal sensor shirts. It is reported however that most of the reviewed projects are experimental and have only been tested on healthy people. The use of smart homes to collect data and assist in identifying slowly evolving events such as cognitive impairment is also discussed by Evans et al. [22]. They describe different presence and contact sensors as well as physiological measuring devices (scales, oximeters, glucometers, etc.) to monitor people in their daily life.

Topol et al. [23] suggest that wireless technology will provide a drastic change in healthcare. Non-invasive sensors can track physiological parameters like heart rhythm, blood pressure, respiratory rate, oxygen, brain waves and others. Nowadays, due to developments in wireless technology, sensors can be applied in body area networks (BAN). The sensors emit a signal (e.g. a physiological parameter) via a wireless communication protocol (e.g. Bluetooth) to a gateway (e.g. a smartphone). The gateway can either decide to process the data locally or to relay the information to a server where the data can be processed. In that case, the user receives the relevant information back through the gateway. In the health and fitness domain, this approach is already gaining popularity. It is expected that during this decade the same will happen for the healthcare domain. Caregivers could remotely access the data of the patient by accessing the server that holds the information of the patient as collected by sensors. Topol et al. [23] suggest that for Alzheimer's disease the following metrics are potentially valuable: vital signs, patient's location, activity and balance.

Kang et al. [24] discuss emerging technologies and possible applications in geriatric settings. They group emerging technologies into two categories: portable (heart rate, blood pressure, activity, oximetry, glucose, sociometer and telephone) and environmental systems (motion, instrumented carpet, door sensor, toilet flush sensor, etc.). For monitoring of dementia patients, it is reported that adoption of technology will only happen if the technology serves a

clear purpose that is meaningful to the user. The features must be practical, compelling, economic and user-friendly. Family caregivers are often willing to pay for technologies that meet their needs in terms of safety. Older study participants consistently reported their willingness to trade privacy for technology if it enables them to remain independent. Customizing data reporting to users' need is seen as a critical step. Primary concerns in the adoption of technology are lack of user friendliness, lack of social/human/caregiver contact and stigma [24].

The following sections provide a more detailed overview of sensing technologies to monitor (1) physical activity, (2) night-time behaviour, (3) gait, (4) ADL, (5) apathy, (6) eating problems, (7) agitation/aggression, and (8) wandering.

2.2.1 Physical activity

Van Someren [25] discusses the use of actigraphy, the long-term assessment of wrist movements, in the context of rest-activity rhythms in healthy aging, Alzheimer's disease and Parkinson's disease. When exploring the characteristics of movement-induced accelerations in healthy elderly, an optimal cut-off frequency of a bandpass filter of 0.25 to 11Hz in order to filter the bias introduced by the gravitational vector and keep all relevant movement information intact was found. Additionally, features to detect tremors in Parkinson's disease and features to describe the variability in day-night rhythm are described. Van Someren concludes that actigraphy is a useful tool for assessing rhythm disturbances in the natural environment of the patient [25].

Fox et al. [26] describe the relation between well-being as assessed by standardized questionnaires and objective assessments of daily energy expenditure using accelerometers. The study including 176 adults aged 70 years or older found that total daily physical activity and amount of time spent on activities of at least moderate intensity were weakly related to quality of life, subjective well-being and physical self-perceptions. Time spent sedentary was weakly and negatively correlated with several mental health indicators [26].

Dakin et al. [27] discuss the role of promoting walking among older people using accelerometers. This work caters for the use of accelerometers as a reliable method of estimating physical activity compared to step counters due to the unreliability caused by slow and abnormal gait patterns. It is reported that the acceptance of such monitoring devices largely depend on ease of wearing, where small devices attached to the wrist or ankle are preferred [27]. Aoyagi et al. [28] explored the relation between physical activity, defined as step count and metabolic equivalents (METs), and healthcare costs, as found in the Nakanojo study, in which the association between habitual physical activity and health in a community of elderly people has been studied. Physical activity was measured with a uniaxial pedometer/accelerometer. People with dementia were found to predominantly fall into the group with the lowest amount of physical activity [28]. Hayes et al. [29] report on the continuous monitoring of walking speed and levels of activity in 14 independently living elderly individuals (average age 89.3 years). The sensors consisted of PIR sensors for detecting activity, magnetic contact sensors, and an array of limited view PIR sensors for detecting walking speed. Wavelet analysis was used to examine variance in activity at multiple time scales. The amount of day-to-day pattern activity in the MCI group was found to be more variable than in the healthy group [29].

Hauer et al. [30] compared physical activity levels as measured by an interview-administered physical activity questionnaire to physical activity levels as measured by an inertia-based

motion sensor (two accelerometers and one gyroscope) in older people with cognitive impairment (MMSE<24) and without cognitive impairment (24<=MMSE<=30). The measurement system includes automatic posture and walking detection for estimating the total MET. Interestingly, the authors assume that the objective data from the motion sensor provide the ground truth. According to them, questionnaires do not provide accurate information since the most common type of activity of frail elderly is often poorly remembered, especially for people with cognitive impairment. The findings of the study demonstrated a good correlation between information from the questionnaires and the motion sensor data [30].

Greene et al. [31] describe a method for the assessment of cognitive decline using quantitative parameters derived from body-worn inertial sensors. They define cognitive decline as a decline of three or more points on the MMSE. They investigated whether quantitative parameters from baseline and changes from baseline to follow-up two years later could be used to automatically classify participants as cognitively impaired or healthy. The inertial sensors were tri-axial gyroscopes mounted to the shank. The participants were pre-screened to have an MMSE score >= 24. Participants were asked do the Timed Up and Go (TUG) test consisting of getting up from a chair, walking at a comfortable speed 3 meters, returning to the seat and sitting down. The following types of quantitative movement parameters were derived: temporal gait parameters, spatial gait parameters, turn parameters and angular velocity parameters. Some of the parameters of changes from baseline to follow-up were shown to correlate with cognitive decline. These parameters led to an accurate classifier close to 90% [31].

Kaye et al. [32] describe a longitudinal community cohort study consisting of deployment of an unobtrusive home-based assessment platform for seniors. The metrics consist of total daily activity, time out of home and walking speed. The sensors used to create these metrics consist of PIR sensors, contact sensors and sensor lines for measuring walking speed. According to the authors, continuous monitoring of a 4-week time window can provide a practical summary metric for future studies, which may wish to compare single time point measures to continuous data. Although sensors were installed in the homes of 265 cognitively healthy elderly persons for an average of 33 months, no results about observed trends are provided [32]. Suzuki et al. [33] studied the correlation between daily activity and cognitive decline in 53 elderly living alone in Japan. The study lasted for approximately one year and consisted of monitoring in-house movements by means of IR sensors. The elderly were split into two groups based on their MMSE score. Elderly with cognitive impairment had a significant lower number of outings and a decrease in indoor movement than elderly with no cognitive decline [33].

2.2.2 Night-time monitoring

Monitoring of night-time activity in dementia patients can be useful since sleep problems can be a major concern for carers and are often the reason for institutionalization. In a literature review of assistive technology for people with dementia during night-time, various modalities were found to be included in studies such as location sensors (magnetic door sensors, ultrasonic transducer, camera, microphone, PIR, piezoelectric pressure mats, GPS, RFID), temperature sensors, movement sensors, air quality sensors and power consumption sensors [34]. Subjective and objective measures of sleep quality are known to have a low correlation which is supported by a study in which nigh-time movements of 35 dementia patients were examined for half a year in a clinical setting, comparing the results of integrated circuit tag monitoring with hourly night-time nursing records [35]. The distance moved per hour was

measured using the monitoring system and the data were compared with hourly night-time nursing records. A low correlation between objective and subjective measures for night-time activity was found.

Chan et al. [36] describe an experimental system to monitor the mobility of a patient. The system consists of a number of PIR sensors installed in a hospital room in a long-stay setting for the elderly. Pre-established activity patterns have been defined by physicians in the form of sensor sequence triggering for the experiments. The mobility results of the single volunteer as derived from the system were compared to the patient's mobility as observed by the staff. Suzuki et al. [37] describe an in-house monitoring system using five PIR sensors. These sensors had been installed in the houses of 14 patients living alone in Japan. The in-house movements were recorded for approximately three months. The following parameters were derived from the data: number of outings, total sleep time, number of sleep interruptions and sleep rhythm. The sleep rhythms were assessed by looking at the standard deviation of the bedtimes and wake-up times. Subjects with impaired cognition (MMSE<24) had significantly less outings and a tendency towards a shorter sleep time compared to the control subjects (MMSE>=24) [37].

Witting et al. [38] explored the circadian rest-activity rhythm of six young and 13 old volunteers and of twelve AD patients using an ambulatory rest-activity monitor. This monitor consisted of an acceleration detector, a predecessor of the now common accelerometers for recording movements of the lower arm. The variables studied consisted of the interdaily stability, the intradaily variability, and the total activity of the 10 most active and 5 least active hours. The young and old volunteers showed no differences in their rest-activity rhythm in any of these variables. A comparison of the old controls versus the AD patients revealed that the rest-activity pattern was markedly disturbed in many of the AD patients and was related to dementia severity [38].

In the study of Cohen-Mansfield et al. [39], sleep was measured in 20 residents of a nursing home. Half of the participants suffered from severe cognitive impairment. The following sensors were included: heart rate monitor, pulse oximeter, impedance pneumography, oral or nasal respiratory flow and actigraphy on the wrist. From these monitoring devices a number of features were derived, such as total sleep time, sleep onset time, sleep efficiency, apnea and sleep-related hypopnea. These features were compared to subjective observations of the patient. It was shown that the subjective observations matched well with the parameters derived from the monitoring devices [39].

In the study of Satlin et al. [40], the circadian motor activity rhythm of 19 severely demented, institutionalized patients with AD was monitored using waist-worn electronic monitors, and as compared to eight control subjects of the same age (71 to 73 years). The diurnal activity was measured by investigating the mean activity counts from 7h-23h; the nocturnal activity was measured by investigating the mean activity counts from 23h-7h. Other features consisted of the twenty-four-hour clock time of the daily activity maximum, total activity of the ten most active hours, and total activity of the five least active hours. People with dementia were shown to have an increase over a factor of two in nocturnal activity and in the proportion of nocturnal to total daily activity. The patients with virtually constant pacing (severe restlessness characterized by nearly constant walking and an inability to remain sitting), showed a marked increase in daytime activity compared to the controls and also showed a significantly decreased amplitude of the circadian activity rhythm. In addition, the AD

patients showed a marked phase-delay, with individual afternoon maxima averaging 2.1 hours later than the controls [40].

Ancoli-Israel et al. [41] report on the use of wrist activity monitoring using actigraphy for monitoring sleep/wake for ten people with dementia in a nursing home setting. All participants had an MMSE score <20. The study examined whether actigraphy can accurately reflect sleep/wake in this population by testing the reliability of a wrist-activity monitor against traditional sleep measurements and against observations of nursing home patients. The traditional gold standard for recording sleep is the polysomnogram (PSG). Sleep was measured with both the PSG and actigraphy (1 minute epoch). The actigraph logged two parameters: total (sum) of all activity and maximum activity during each epoch. Two certified polysomnographic experts annotated the PSG records for wake and sleep. The study revealed that recording EEG (part of the PSG) was extremely difficult for an institutionalized population. In addition, the EEG records showed diffuse slowing, which made it difficult to score sleep or wake. Despite this observation, a high correlation was found between EEG and wrist-worn actigraphy. Additionally, the observations of the nursing home patients corresponded very well with the sleep/wake activity based on actigraphy [41].

Spring et al. [42] examined the effect of a night-time monitoring system on caregiver well-being. Sleep problems are often reported as having a major impact on the caregiver since it interferes with their sleeping. The prototype of the night-time monitoring system in this study consisted of an information centre at the bedside of the caregiver and sensors at the bed of the patient as well as in other strategic areas in the house. The study included 26 caregiver/care recipient dyads who received the night-time monitoring system and 27 who did not receive the system. The average MMSE of the patients was 13.36 (range 2-21). The caregivers using the night-time monitoring system reported improved peace of mind compared to the caregivers who did not use the system [42]. In another study, an infrared sensor system was used to detect the presence or absence from a person's bed [43]. Using this system, the rest-activity patterns of two elderly people with dementia was assessed over a period of three months. For both subjects, frequent activity peaks and absences were often observed during the night [43].

2.2.3   Gait

Gait describes the pattern of movement of the limbs during motion. In the review paper of Snijders et al. [44], different clinical methods for the assessment of the relation between cognition and gait are described. Both routine examinations such as gait initiation, step height, width of base, arm swing and path deviation, as well as quantitative assessment such as accelerometers, pressure sensitive in-soles or an electronic walkway are mentioned. For the routine examinations, gait speed is mentioned as an important parameter relating to a number of health problems in elderly. Especially dual task assessment of gait is seen as a means to provide important information about cognitive functioning, in particular attentional deficits. As for the quantitative assessment, locomotion rhythmicity, stride variability or changes in left-right synchronisation are mentioned as important parameters [44].

Gillain et al. [45] compared gait parameters of healthy elderly, individuals with MCI and AD patients using a three-axis accelerometer in order to investigate whether accelerometer data provide more useful information than conventional clinical tests. It was shown that under certain conditions the accelerometer approach was more accurate than validated clinical tests (timed up and go, pull and one leg balance test). For the accelerometer, the following features

were examined: gait speed, stride frequency, stride length, stride regularity and stride symmetry [45].

The dual task paradigm was used in a study by Maquet et al. [46] to compare gait characteristics of healthy elderly, MCI patients and AD patients. For this purpose a 20-second period of stabilized walking was used to calculate stride frequency, stride length, symmetry and regularity. This was measured with an accelerometer. The walking speed was determined using a system with electrical photocells. A specific gait pattern could be determined for each cohort profile. For the simple task, the walking speed, stride length and regularity were significantly lower in AD patients compared to healthy elderly and MCI patients. The stride frequency was significantly reduced in MCI patients compared to healthy controls. During the dual task, the walking speed appeared significantly different between the three groups. No stop was observed in the controls in contrast to some MCI and AD patients. Furthermore, it was shown that healthy elderly showed a significantly better step symmetry during dual task than both patient groups [46]. Similar results were obtained by Lamoth et al. [47] who studied 13 elderly people with dementia and 13 elderly people without dementia as they walked at a self-selected speed with and without performing a verbal dual task for 3 minutes. The accelerations of the trunk of the body were measured using tri-axial accelerometers. The following features were analysed: walking speed, mean and variability of stride times, and stochastic dynamical measures such as regularity (sample entropy, long range correlations) and local stability exponents of trunk accelerations. Cognitively impaired elderly were found to show significantly more changes in gait variability than healthy elderly when comparing normal versus dual-task walking [47].

Hagler et al. [48] describe a system for continuous and unobtrusive in-home assessment of gait velocity. Estimation of the walking speed is an important parameter since a decline in walking speed can precede the development of dementia. By means of a sensor array of restricted view PIR motion detectors, gait velocity can be estimated. Installing such a sensor array in a home environment has the advantage of easily allowing a longitudinal study. It was shown that walking speed can be estimated accurately (average error of +/-7% for a non-calibrated system) [48].

In a study by Kearns et al. [49], a sensor network to measure daytime locomotion was deployed in an assisted living facility. The daytime locomotion was measured for 14 elderly residents as they traversed a shared living area in an attempt to relate cognitive functioning to the natural variability of movement paths unconstrained by a test environment. The elderly wore compact tag transponders at their wrist. The sensors for detecting the locomotion were mounted to the wall in each corner of regular common space. It was shown that increased temporal variability in gait and balance can be observed in dementia patients [49].

2.2.4   Activities of Daily Living

Virone [50] describes a pattern recognition model for assessing behavioural rhythms based on motion detection sensors. The model is based on assessing time intervals a subject spends in each room of the home environment. Using these time intervals, a circadian pattern can be established. Additionally, similar metrics can be established for specific ADLs that are known to occur frequently and that have a particular order of rooms to be passed. By examining the resulting patterns and comparing the daily pattern to the statistics of past patterns deviations from the normal behaviour could be detected [50].

Franco et al. [51] propose a method for medical telesurveillance to detect and quantify a nyctheremal shift. Nyctheremal rhythm is a rhythm which lasts exactly 24h and is synchronized with the environmental light-darkness cycle. For the purpose of surveillance, an experimental platform consisting of a 50m2 flat equipped with IR sensors were built. In addition, environmental parameters such as temperature, humidity and illumination were measured. Based on the sensor data activities were characterized into four categories: ambulatory, generic, cooking/eating and unassigned. Based on this data, daily profiles can be established, consisting of a sequence of these categories. By investigating such profiles over a longer period of time, a typical daily sequence can be determined. Then, based on next daily patterns, deviations from this rhythm can be determined quantitatively, e.g. by means of the Hamming distance. Unfortunately, no results are provided with regard to the performance of the system [51].

2.2.5 Apathy

David et al. [52] explored the relation between apathy and locomotor activity in 30 AD patients and 15 healthy controls. Apathy was assessed with the Apathy Inventory (AI). Locomotor activity was assessed using a wrist-worn actigraph for 75 minutes, during which a neuropsychological and behavioural examination was performed (60 minutes) followed by 15 minutes of free activity. The mean motor activity, total motor activity and the number of minutes without movement were registered. It was found that AD patients showed lower motor activity than healthy subjects. Additionally, AD patients with apathy had lower motor activity than AD patients without apathy [52]. Similarly, in a study conducted by David et al. [53], the relationship between apathy and daytime motor activity in AD was measured using ambulatory actigraphy. More than 100 AD outpatients participated in the study and wore an actigraph on their wrist during seven consecutive 24-hour periods to evaluate motor activity. Two groups were formed based on participants' NPI apathy scores. Individuals with apathy had significantly lower daytime mean motor activity than AD patients without apathy. The night-time mean motor activity did not significantly differ between the two groups [53]. Mulin et al. [54] explored the relation between apathy and sleep/wake patterns in 103 non-institutionalized AD patients who wore an actigraph on the wrist continuously for a week. Apathy was assessed using the NPI. AD patients with apathy had significantly lower daytime mean motor activity, higher wake after sleep onset, time in bed, sleep latency and night-time mean motor activity [54].

2.2.6 Eating problems

In a study by White et al. [55], the relationship between weight loss, which often occurs in AD, and behavioural symptoms was explored in institutionalized patients (n=32) for the duration of six months. Patients were weighed monthly and the NPI-NH was conducted during baseline, at month 3 and at month 6. Accelerometers were worn to monitor physical activity. The results show that the BMI was negatively associated with the baseline NPI-NH score, indicating that subjects with low BMIs were more likely to have higher frequency and severity of behavioural problems. Individual behaviour scores for agitation/aggression, depression, irritability/lability, aberrant motor behaviour, night-time behaviour and appetite/eating at baseline were negatively correlated with baseline BMI. Both agitation/aggression and disinhibition were negatively correlation with weight change. Hence, this study suggests that behavioural disturbances play a role in low body weight and weight loss in AD patients [55].

2.2.7 Agitation/aggression

In the paper by Mahlberg et al. [56] the motor activity levels of 24 patients with probable dementia of the Alzheimer type and agitated behaviour was measured. The activity level was monitored with an actigraph worn on the wrist of the non-dominant hand. Both the actigraphy data and the NPI were found to distinguish between patients who received medication and patients who received placebo treatment. However, the two measures did not correlate. Hence, it was concluded that the NPI describes different aspects of neuropsychiatric symptoms of dementia than actigraphy [56].

Bankole et al. [57] explored whether inertial wireless body sensor networks (BSN) can be used to objectively detect and quantify agitation in patients in a nursing home setting. Agitation and aggression were measured in six patients by means of the Cohen-Mansfield Agitation Inventory (CMAI) and the Aggressive Behaviour Scale (ABS). The BSN nodes, i.e., the individual sensor devices, were applied at three positions on the body for three hours while behaviour of the patients was annotated simultaneously. The BSN inertial data was processed for extracting jerky and repetitive movements. BSN features were found to relate reasonably to the annotation data [57].

2.2.8 Wandering

Wandering is a behavioural disorder which can occur in dementia patients. Wandering can cause stress for caregivers. GPS systems can be used to track patients who show wandering behaviour as described in Shoval et al. [58] and Faucounau et al. [59]. Although both patients and caregivers seem to appreciate the possibility of electronic tracking, additional needs have been expressed such as being able to remove the system [58, 59].

3 Evaluating the Impact of Dem@Care

It is evident that a growing body of research supports the benefits of ICT solutions for PwD, their informal caregivers, and by extension society as a whole, however, the impact assessment of ICT projects remains a challenge; for example, the reliable and valid scientific measurement of anticipated quality of life for end-users, and the socio-economic impact for direct stakeholders, healthcare systems, and national economies [1]. In assessing the personal and social impact of the Dem@Care system, it is necessary to describe what we have said the impact should be, how we will recognise that this impact has occurred (i.e. illustrate what the impact looks like), and how, where, and when this impact can be measured. Appropriate outcomes therefore need to be determined for each area of impact, with reliable and valid indictors and corresponding measurement tools that can demonstrate the extent to which Dem@Care has achieved its intended outcomes

3.1   Goals of the Dem@Care System

The goal of the Dem@Care project is to develop a closed-loop management solution for people with early or mild-stage dementia through multi-parametric remote monitoring and individual-tailored analysis of physiological, behavioural and lifestyle measurements. This solution will be tailored for three specific operational scenarios: the lab (Dem@Lab), the nursing home (Dem@Nursing), and the home (Dem@Home). Although these three clinical scenarios are distinctly different, the components and combinations of components are used in similar ways in each setting, which facilitates a single impact evaluation strategy. Successful attainment of the Dem@Care goals will allow us to answer the following research questions across the three pilot settings:

– For Dem@Lab:

   o   Can the Dem@Care system be used to differentiate between early stage AD and related disorders from patients with mild to moderate stages of the disease and healthy elderly?

   o   Can the Dem@Care system assess the impact of behavioural disturbances, in particular apathy, and the completion of instrumental activities of daily living?

   o   Can the Dem@Care system assess the impact of cognitive decline based on speech and vocal characteristics?

   o   Can the Dem@Care system obtain data using actigraphy coupled with an audio-video setting that is comparable to data obtained with a conventional examination in the assessment of cognitive and neuropsychiatric symptoms of dementia?

   o   What is the acceptability among participants of using the Dem@Care system during a standard consultation in a memory centre?

   o   What is the acceptability of introducing a follow-up monitoring system based on the use of ICT within participants' own homes?

– For Dem@Nursing:

   o   What is the usefulness of the Dem@Care technology in this context?

   o   What is the usability of the Dem@Care technology in this context?

- o Can the information from the Dem@Care sensor system support staff members reasoning when doing assessments status and evaluations of interventions among people with BPSD?

- o Can support of people with BPSD be more effective with the support of the Dem@Care technology?

− For Dem@Home:

- o Is the system acceptable in the home; is it non-intrusive, and useful to the person with dementia and their family?

- o Are the functional requirements reflective of the reported needs of the person with dementia, as personally reported and reported by caregivers?

- o What is the functional status of the person with dementia as operationalised in the five domains, and can the system optimise status in these areas?

- o How autonomous and independent is the person with dementia, and can deployment of the system support this autonomy?

There are four beneficiary groups, namely the PwD, the family of the PwD/informal caregivers, the health care specialist (e.g. general practitioner, geriatrician, psychiatrist, elderly care specialist, etc.) and the nursing personnel. Table 1 provides an overview of the extent to which each of these four groups may benefit from the identified assets. Typically each asset has one or more primary beneficiaries (indicated with 'P') and possibly one or more secondary beneficiaries (indicated with 'S').

Table 1 – Assets and beneficiaries

Asset	PwD (enablement, quality of life)	Family/informal carer (relief and respite)	Specialist (improved diagnosis)	Nursing (reduced staff needs)
Dem@Home	P	P	S	
Dem@Nursing	P	S	S	P
Dem@Lab			P	
myLifeStory	P	P		S
DemVoice			P	
DemSleep	P	S	S	S
DemVisual	P	P	S	P
DemBracelet	S	P	S	S

3.2 Evaluation methodology

Social impact assessment typically combines evidence from a formative and a summative evaluation of project. Formative evaluations take place during the project; for example, during co-design and pilot evaluations. Summative evaluations take place at the end of a project and, as the name suggests, sum up what has happened during the project and the effects of these project activities. In both cases the project evaluation generally considers both implementation and outcomes. Implementation evaluations are concerned with content (i.e. did the programme do what it said it would do?), quality (i.e. how well did the programme do

it?), and satisfaction with the final product. This satisfaction can also be evaluated against stakeholder perceptions of the intended product. In contrast, outcome evaluations focus on changes in awareness, knowledge, attitudes, behaviour, results, and accomplishments (i.e. what difference did the programme make?). This report is mainly concerned with evaluating outcomes, as implementation will be evaluated as part of the pilot reports (WP8) and the project management reports (WP1). However, aspects of implementation evaluation will be addressed in order to support some the claims made when determining personal and societal impact; for example, identification of the Dem@Care activities that support expected outcomes, and the acceptability and usability of the final system as this is likely to significantly influence the perceived benefits of the system for the various end user groups.

3.2.1 Outcomes, indicators, and measures

As previously stated, appropriate *outcomes* must be identified for each area of impact, with reliable and valid *indictors* and corresponding *measurement tools* that can demonstrate the extent to which these intended outcomes have been achieved.

Outcomes represent the results of the Dem@Care programme. They can encompass changes in knowledge, skill, attitudes, behaviour, motivation, decision-making, policies, and conditions, and they occur among individuals, communities, organisations, and systems. Not all outcomes will be achieved at the same time; instead chains of outcomes will be expected to build up over time. These chains typically involve:

1. Short-term learning (ST)

   - Acquisition of new knowledge

   - Results in changed attitudes, opinions and values, increased skills, changed motivations, and altered aspirations.

2. Intermediate (Medium-term) behavioural changes (MT)

   - Actions taken as a result of that knowledge

   - Results in modified behaviour, changes decisions, practices, policies, and social action.

3. Long-term changes in condition (LT)

   - Conditions that change as a result of ongoing and consistent changes in action

   - Results in changed human, civic, economic, and environmental conditions.

   - These are not completely within the control of any programme, but they are changes that a programme hopes to contribute to over time.

With many ICT solutions such as Dem@Care, it is important to note that truly meaningful results are often only obtained after a lengthy period of deployment of the system.

An *indicator* is the evidence or information that illustrates that an intended outcome is being achieved. It provides the answer to the question "*How will we know change has occurred?*" Indicators must be clear, unambiguous, tangible, and observable otherwise they cannot be measured. They must be meaningful, such that they present information that is important to key stakeholders, and valid so that they truly represent the outcome they are associated with.

They should be practical to collect and useful in terms of facilitating programme improvement. A strong indicator would typically comprise of four components:

1. The amount of change that indicates success and sets the target for the programme (how much)

2. The target population (who)

3. The condition, behaviour, or characteristic that is to be measured (what)

4. The timeframe in which the change should occur (when)

The ***measurement tools*** corresponding to each indicator must also be valid, in that they truly measure what they purport to measure, and reliable, such that they can capture the change in status specifically attributable to Dem@Care. Some indicators can be measured directly, for example physiological or cognitive improvements, and measurement change can then be quantified (e.g. 10% increase, 5% reduction). Other outcomes may only be measurable with reference to another activity or as behavioural responses in given situations. These indirect measures cannot be quantified in the same way, and they will need to be evaluated as 'more' or 'less' than a baseline measure. The Dem@Care evaluation will use direct measures where possible, although some impacts such as the subjective quality of life will necessarily require more subjective measures (e.g. focus group discussion, and stakeholder testimony and opinions). Thus a combination of objective and subjective measures (mixed-method approach) will be required to fully comprehend the overall impact of the Dem@Care solution. From a practical perspective, it will be important to minimise the number of measurement tools required while maximising the amount of data collected. Finally, in cases where psychometric measures are required, instruments will be selected that are appropriate to a mild- to mid-stage dementia population and their carers, and ones which can be compared to other related international research studies.

As can be seen from section 3.1 above, three distinct sets of outcomes are expected from the Dem@Care programme: personal, social, and scientific. The overall evaluation approach will be consistent across the three areas, although the ease with which the target outcomes can be evaluated differs between the categories, as does the balance of quantitative and qualitative measures that will be used in each case. As a result, a three-tiered outcome evaluation plan has been created that separately assesses each category in order to arrive at an overall outcome evaluation of the programme. These plans are presented in the following sections. In each case, the specific characteristics of impact assessment within that category are discussed, including assessment issues and the likely barriers to and facilitators of change in that area. An impact assessment matrix is then presented which contains expected outcomes, corresponding outcome indicators and measurement tools, and the Dem@Care activities that are likely to contribute to the achievement of each.

3.2.2   Stakeholder involvement

In general, stakeholder impact assessments deal with project-specific impacts on the people directly affected by the project and the communities in which they are situated. Stakeholders are therefore an intrinsic part of the dementia care environment that Dem@Care aims to influence, but they also play an important role in the evaluation of that impact. As such, they are indirectly part of the innovation process itself [60]. For the purposes of this report, the

term 'stakeholder' will apply to all interested parties connected with the Dem@Care project. Dem@Care stakeholders can be categorised into three broad categories:

1. End-users; those individuals that interact directly with the Dem@Care system itself. This includes PwD, informal caregivers, clinicians, formal care staff, researchers, and technicians.

2. Academics and professionals; those who want to develop and further clinical, technical, and ethical state-of-the-art with regard to dementia care and to the wider use of sensing technologies.

3. Policy makers at the intermediary or government level; those individuals who are interested in using research to support and drive policy, or to facilitate the transfer of scientific knowledge to society.

A comprehensive evaluation of the impact of the Dem@Care project requires input from each of these stakeholder groups, although not all expected outcomes may be assessed to the same extent for each group. As would be expected from programme whose aim is to provide a technical solution to a group of end-users, this group will be the most closely connected to the project. They are involved in the co-design of the system, as a target audience for dissemination, and most importantly in each of the pilot studies. They will provide the data that will determine the personal impact of Dem@Care, and will contribute to the evaluation of societal impact. Academics, professionals, and policy makers are also important target audiences for dissemination, and their evaluations will be required to determine scientific impact and to supplement those of the end-users when evaluating societal impact.

3.3   The personal impact of Dem@Care

The Dem@Care programme is expected to impact PwD, their informal caregivers, clinicians, and formal care staff at a personal level. There are two sides to this concept of personal impact, real and perceived, and it will be important to distinguish between the two and attempt to understand the way in which they interrelate. A 'real' impact can be measured with objective data that verifies its existence. In contrast, a 'perceived' impact is purely a subjective personal point of view about that impact [61].

In general, the expected outcomes at this micro-level can be grouped into three categories:

- Independence – although most common conceptualisations equate independence with absence of reliance on others, for older people themselves it is a broader concept that encompasses self-reliance, self-esteem, self-determination, purpose in life, personal growth, and continuity of the self [72]

- Sense of Improvement – physiological and psychological (cognitive, behavioural, and emotional) impacts that represent changes to quality of life, stress, and burden.

- Security and Safety – reduction of danger and risk

While all three categories are relevant to PwD, independence and sense of improvement are most relevant for informal carers and sense of improvement alone for clinicians and formal care staff.

3.3.1 Examining quality of life

One of the core aims of the Dem@Care system is to help improve the quality of life (QoL), autonomy, and sense of independence of the PwD and thereby improve the QoL of their informal caregiver. There is general agreement that QoL requires a comprehensive assessment rather than concentrating purely on physical and functional capabilities alone [62, 63]. It consists of both objectively measurable factors and a subjective sense of what it means to have a 'good life' for the individual involved. This subjective measurement is in turn influenced by a person's physical health, psychological state, personal beliefs, values, goals, expectations, concerns, social relationships, and their physical and cultural environment. Additional aspects to be considered that may improve quality of life of PwD and carers alike, as a result of an ICT intervention are: perception of safety, level of user satisfaction with the ICT solution/Service offered, access to extra services and to those that are not offered with traditional public care, and additional face-to-face time with clinical researchers. The latter is particularly important when evaluating pilot projects such as Dem@Care that incorporate a higher degree of time spent with a research than might be expected from the final commercially available product. ICT solutions such as Dem@Care must mediate the relationships between these varied predictors of QoL in order to improve this concept for an individual, and accurate measurement of QoL therefore requires tools to measure both the objective and subjective aspects of the lived experience.

Examining quality of life for PwD

QoL needs to be measured relative to improvement in cognitive, motor and social function indices and autonomy, and there are many rating scales available for people with dementia [62]. Given the subjective aspects of this measurement, the perception of the PwD is preferable to proxy ratings [63], although in later stages of dementia proxy ratings can be useful [64]. In a recent review by Moniz-Cook and colleagues [62], Quality of life in Alzheimer Disease (QoL-AD) appears to be the measurement tool of choice for individuals with mild to moderate dementia [65]. It provides a special conceptualisation of QoL for PwD in the following domains: Physical and mental health (physical status, memory, energy, and mood); Social contact (family, friends); Attachment (marriage); Enjoyment of activities (leisure); Ability to contribute (being useful); and Financial situation. An alternate measure, the Dementia Quality of Life Scale (DEMQoL) is equally valid in mild to moderate dementia (MMSE scores $\geq$ 10) and the DEMQoL-Proxy is the best available proxy measure with this population [66]. Both measures will be introduced in the second pilot and this data will be used to evaluate if both will remain in pilot three, or if one measure is sufficient

Examining quality of life for informal carers

Carer Qol requires a measurement tool that encompasses both a description of the caring situation and an evaluation of the impact of formal care. The Carer Quality of Life scale (Carer-QoL) integrates the measurement of these two components into a short, easily administered scale [67]. It can also be used in the context of economic evaluations as it provides a clear picture of the impact that informal care has in a specific context, and it can be useful when a full cost-consequence analysis is not feasible. It shows good construct validity for this population [68].

3.3.2 Outcomes for the person with dementia

The expected personal outcomes for the PwD and the assessment plan to evaluate these outcomes are presented in

Table 2 below. Data will be required from the PwD, and proxy-data from their informal or formal carers as appropriate, in order to complete this assessment. It is expected that most of the input required will be collected during the three Dem@Care pilot studies; original protocols for the pilot evaluations are available in deliverable D8.2 (Evaluation Protocol), and these will be updated with for each pilot study and presented in the associated pilot evaluation report (D8.3, D8.4, and D8.5). An additional end-of-project interview will be scheduled to capture the perceptions of the overall acceptability and usefulness of Dem@Care to the PwD and to their caregivers.

Table 2 Matrix for assessing the personal impact of Dem@Care for the PwD

OUTCOME	INDICATORS (Time frame)	MEASUREMENT	CONTRIBUTING ACTIVITIES
Independence			
PwD is better able to take care of themselves	– PWD more educated about their condition (ST) – PwD actively participates in their own treatment (ST) – Sustainable at home treatments (ST) – Reduced carer burden (INT) – Reduced hospitalisation for PWD (LT) – 10% reduction in time spend in nursing care (LT)	– Metrics around feedback accessed, education guides downloaded, and increased awareness evident in semi-structured interviews (pilots) – High usability and acceptability rating and evidence that PwD can drive their interaction with the Dem@Care system in the absence of the researcher – Reduced carer burden scores (as measured by the Carer-Qol), relative stress scores (as measured by RSS), and perceived stress scores (as measured by PSS). – Improved carer quality of life (as measured by the Carer-Qol). – Systematic observation of reduced Behavioural and Psychological Symptoms of Dementia (BPSD which directly reduces the need for care attention. – Interview: self-reports and carer reports to determine the reduction in formal care required.	– Development of a Patient Interface that enables PwD @Home to receive feedback that has either been manually created by a Clinician, or generated by the system following set clinical rules within sleep, eating, physical activity, social contacts or mood areas, and that provides instrumental support to PwD @Home for: o Reminders, Memory enhancers, Assistance with daily activities, sleep, and physical activities o Lifelogging and provision of cognitive rehabilitation interventions – Improved clinical assessments and the greater possibility of evaluating care interventions. – Achieving short-term outcomes such as earlier diagnosis, earlier intervention, and an increase in independence will positively influence the

			attainment of MT and LT outcomes.
OUTCOME	**INDICATORS (Time frame)**	**MEASUREMENT**	**CONTRIBUTING ACTIVITIES**
Facilitate daily life	– PwD has an increased sense of autonomy (ST) – PwD demonstrates sustained independence in daily living (ST) – Improve/maintain the physiological, psychological, and social condition of the PwD (MT) – Remain at home for longer (LT)	– Sustained ability to carry out ADL (as measured by Dem@Care) – Improvement in ADL identified as problematic in the initial assessment (as measured by Dem@Care). – Improved scores on the Bristol-ADL and Everyday Competence Questionnaire, and reduced scores on the Scale of Older Adults' Routine *Note: Dementia is a progressive disease so it will not be realistic to expect improvements in assessment metrics over longer periods of time. A slower rate of decline is more likely. Proxy assessments by carers and clinicians will be required to establish the impact of Dem@Care in situations where overall function has declined.* – Interview: self-reports and carer reports – The physiological, psychological, and social condition of the PwD will each be measured separately (see below) and they combine to facilitate an more autonomous daily life for the PwD – Indirect measurement of LT outcome by demonstrating improvements in independence and autonomy in each of the five domains over the course of the project.	– Comprehensive stay-at-home Dem@Home solution that provides analysis, support, and interventions in a timely and effective manner across each of the five domains assessed. This will be achieved by delivering the requirements of the Dem@Care system as detailed in D2.6 – Development of a Patient Interface that provides instrumental support to PwD @Home for sleeping (music), waking up (sound), and any kind of pre-programmed reminder for stimulating expected activities to happen – Development of a Clinician Interface that enables Clinicians and Carers @NursingHome to see previous feedback for a PwD, so that they may advise the PwD
Stabilise / Delay advancement of condition	– 10% earlier diagnosis of Dementia (ST) – Early detection of health status degradation (MT) – More Timely Intervention (MT)	– Evidence that diagnosis is occurring at an earlier age – Evidence that the rate of accurate diagnosis is increasing – Evidence of the identification of problematic data patterns in Dem@Care that can be used to trigger and tailor effective interventions – Evidence that better clinical assessments lead to more timely and therefore more successful, interventions.	– Provision of physiological, cognitive, emotional, and social support via the Dem@Care system.

OUTCOME	INDICATORS (Time frame)	MEASUREMENT	CONTRIBUTING ACTIVITIES
Sense of Improvement			
Improve physiological condition of PwD	– PwD shows increased levels of physical activity (ST) – PwD has improved quality and duration of sleep (ST) – PwD has improved physical condition (LT) – PwD has improved eating patterns (MT)	– Increased evidence of physical activity as scored by the Rapid Assessment of Physical Activity and the Physical Activity Scale for the Elderly – Evidence of improved physiological data patterns as measured by Dem@Care. – Reduced scores on the Pittsburgh Sleep Quality Index, Epworth Sleepiness Scale, and Insomnia Severity Index, and as measured by the NPI-NH scale – Improved sleep patterns as measured by Dem@Care – Increased scores on the mini-nutritional assessment and evidence of appropriate eating patterns as measured by Dem@Care – Interview: self-reports and carer reports to supplement psychometric and Dem@Care data in each area, and to capture perceived levels of improvement	– Physiological, sleep, and nutrition monitoring and feedback – Improved physical activity video recording during assessment and diagnosis (@Lab) – Physical activity, sleep, eating and nutritional interventions and educational guides – Early intervention based on timely identification of patterns of deterioration
Improved psychological condition (PwD)	– PwD has increased feelings of well-being (ST) – PwD shows stable non-negative mood patterns (ST) – PWD has reduced BPSD symptoms (ST) – Early identification of deterioration in non-physical symptoms (MT)	– Reduced scores on the Geriatric Depression Scale and the DE Jong Loneliness Scale – Improved Quality of Life (Qol-AD; DemQol, Proxy) – Changes in BPSD symptoms using the NPI-NH scale and evidence of positive & stable mood patterns in Dem@Care – Timely indication of deterioration in non-physical symptoms as measured by physiological sensors (for example, sleep, apathy, and potentially depression), which facilitates earlier intervention – Interview: self-reports and carer reports to supplement psychometric and Dem@Care data in each area, and to	– Mood and social interaction monitoring and feedback – Mood and social interaction interventions and educational guides – Early intervention based on timely identification of patterns of deterioration – Systematic clinical assessment with NPI-NH

		capture perceived levels of improvement	
OUTCOME	**INDICATORS (Time frame)**	**MEASUREMENT**	**CONTRIBUTING ACTIVITIES**
Improve cognitive condition of PwD	– PwD shows stable levels or a slow-down in decline of cognitive skills (ST) – PwD shows stable or slower decrease in overall cognitive condition (LT)	– Evidence of sustained or more slowly decreasing cognitive skills as measured in Dem@Care by sustained ADL skills, and potentially by improved or new ADL skills – Cognitive improvements as measured by cognitive interventions hosted through Dem@Care (e.g. life-logging) – Interview: self-reports and carer reports to supplement psychometric and Dem@Care data in each area, and to capture perceived levels of improvement	– Cognitive and (I)ADL monitoring and feedback, including reminders and memory enhancers – Improved (quicker and more effective) cognitive testing during assessment and diagnosis (@Lab) – ADL/IADL intervention and support – Cognitive rehabilitation interventions – Early intervention based on timely identification of patterns of deterioration
Improve social condition of PwD	– PwD shows increased levels of social interaction (ST) – PwD shows reduced levels of loneliness (ST) – PwD is well integrated into society (LT)	– Increased evidence of social interaction as scored by the Lubben Social Network Scale, and as seen in the social interaction data patterns measured by Dem@Care. – Increased sense of well-being (as measured above) – Interview: self-reports and carer reports to supplement psychometric and Dem@Care data in each area, and to capture perceived levels of improvement – It will be difficult to measure longer-term integration into society during the course of this project; however, research demonstrates that increased social interaction in the short-term will, if sustained, lead to better integration in the long-term.	– Cognitive and (I)ADL monitoring and feedback, including reminders and memory enhancers – ADL/IADL intervention and support – Cognitive rehabilitation interventions – Early intervention based on timely identification of patterns of deterioration
Security and Safety			
Increased sense of security and safety	– PwD feels safe in the home (MT) – Carer feels that the PwD is safe in the home (MT)	– Number and accuracy of alerts triggered by the Dem@Care system – Interview: self-reports and carer reports to capture usability and usefulness of the reminder and alert functionality in Dem@Care	– Real-time feedback and assistance – Positive feedback loop – Alarms – Adaptive feedback mechanisms for dealing with hazardous situations

Note: ST, short-term; MT, medium-term; LT, long-term.

3.3.3 Outcomes for the informal caregiver

The expected personal outcomes for informal caregivers and the assessment plan to evaluate these outcomes are presented in Table 3 below. Data will only be required from informal caregivers in order to complete this assessment. This data will be collected as part of the @Home pilot studies and during the end-of-project interviews, both of which have been outlined above.

Table 3 Matrix for assessing the personal impact of Dem@Care for the informal caregiver

OUTCOME	INDICATORS (Time frame)	MEASUREMENT TOOLS / EXPECTED RESULTS	CONTRIBUTING ACTIVITIES
Independence			
Facilitate daily life	– Simple, easy to use system that does not increase carer burden (ST) – Time efficient provision of care (ST) – Accurate and comprehensive information about the condition of the PwD (ST) – Recognition of possible issues that may arise (ST)	– High usability and acceptability rating – Clear carer interaction with the Dem@Care system – Metrics around feedback accessed, education guides downloaded, and increased awareness evident in semi-structured interviews (pilots) – Improved psychological condition of the carer – Interview: carer self-report to capture perceived levels of improvement	– Comprehensive Dem@Home system that is acceptable and easy to use – Successful attainment of the personal impacts for the PwD
Sense of Improvement			
Improved psychological condition of carer	– Improved quality of life and sense of well-being (ST) – Reduced responsibility, burden, and stress (ST) – Carer has more time available for themselves (MT) – PwD stays at home for longer	– Improved carer quality of life scores as measured by the Carer-Qol – Reduced scores on the relative stress scale (RSS) and on the perceived stress scale (PSS) – Interview: carer self-report (perceived improvement) – Carer stress is often the main reason why a PwD goes into a nursing home, so an indirect measure of reduced carer stress would be a reduction in the	– Successful attainment of the personal impacts for the PwD leading to a reduction in hands-on care required by the carer – Provision of safety and security alerts in high-risk domains

OUTCOME	INDICATORS (Time frame)	MEASUREMENT TOOLS / EXPECTED RESULTS	CONTRIBUTING ACTIVITIES
(LT)		number of PwD entering nursing homes, or a delay in entry to formal care.	
OUTCOME	INDICATORS (Time frame)	MEASUREMENT TOOLS / EXPECTED RESULTS	CONTRIBUTING ACTIVITIES
Improved economic position of carer	– Cost-efficient provision of care (MT) – Carer can maintain active work or rejoin the active workforce (MT)	– It is unlikely that any direct measures (i.e. number of carers remaining in work) will be possible in the time frame of this project, so these outcomes will be assessed qualitatively using carer self-reports in a semi-structured interview – Perceived usefulness of Dem@Care in relation to the expected cost	– Establishment of likely costs for the Dem@Care system (WP9) including the ability to derive costs for different combinations of exploitable components (as per the toolbox approach) – Successful attainment of the personal impacts for the PwD

Note: ST, short-term; MT, medium-term; LT, long-term.

3.3.4 Outcomes for clinicians and formal care staff

The expected personal outcomes for clinicians and formal care staff, and the assessment plan to evaluate these outcomes, are presented in Table 4 below. This data will be collected as part of the @Lab and @Nursing Home pilot studies and during the end-of-project interviews.

Table 4 Matrix for assessing the personal impact of Dem@Care for the clinician and formal caregiver

OUTCOME	INDICATORS (Time frame)	MEASUREMENT TOOLS / EXPECTED RESULTS	CONTRIBUTING ACTIVITIES
Sense of Improvement			
Facilitate timely diagnosis	– Accurate and comprehensive information about the condition of the PwD (ST) – Elicitation of new clinical knowledge for improved diagnostic precision and effectiveness (ST) – More accurate predictions	– Accurate and comprehensive information about the condition of the PwD provided by Dem@Care – Evidence that using Dem@Care improves diagnostic accuracy over and above neuropsychological measures alone – High usability and acceptability rating from clinicians – Clear clinician interaction with Dem@Care	– Dual measurement of diagnostic tests using traditional neuropsychological tasks and Dem@Care sensor technology – Measuring aspects of gait using the dual-task paradigm (see @Lab trial) provides valuable information about attentional deficits that may contribute to early diagnosis – Measuring activity can also contribute to

	(ST)	– Interview: clinician self-report to capture perceived levels of improvement	the accurate diagnosis of specific non-physical symptoms
OUTCOME	**INDICATORS (Time frame)**	**MEASUREMENT TOOLS / EXPECTED RESULTS**	**CONTRIBUTING ACTIVITIES**
Facilitate timely diagnosis **(continued)**	– Potentially increased insights of Clinicians in how individual patients perform directed and semi-directed tasks in the diagnostic room, and getting objective indications of cognitive decline. (ST) – 10% increase in diagnosis of MCI and mild Dementia (MT) – More efficient diagnostic process in term of time and cost (MT) – Help a larger number of people (MT)		– Development of a Clinician Interface that visualises activities and measurements for a chosen time period. Deviations from statistical norms (@Lab it should be healthy subjects) are highlighted (1-2 STD and >2 STD).
Facilitate formal care-giving	– Accurate and comprehensive information about the condition of the PwD (ST) – Recognition of possible issues that may arise (MT) – More efficient care process in term of time and cost (MT) – Potential improved follow-up of PwD by Clinicians and Carers @NursingHome	– Systematic researcher observation – Accurate and comprehensive information about the condition of the PwD provided by Dem@Care – Efficiency can be assess through a comparison of clinical assessment with and without the information from the Dem@Care system when assessing BPSD with the NPI-NH measure – High usability and acceptability rating – Clear care staff interaction with the Dem@Care system and reduced care-staff burden	– Personalised feedback – Development of a Clinician that shows Problems and the Events causing them, for a chosen time period. This facilitates determining if a PwD is developing certain types of problems.

	(MT)	– Interview: care staff self-report	

Note: ST, short-term; MT, medium-term; LT, long-term.

3.4 The societal impact of Dem@Care

In general terms, the social impact of academic research is defined by the degree to which the research contributes to and creates an understanding of the development of societal sectors and practice (such as industry, education, policymaking, and health care), the goals they aim to achieve, and to resolving problems and issues evident in those sectors of society [60]. Evaluating social impact is often quite difficult as these impacts occur on a much wider scale than those personally relevant to individual stakeholders; for example, at strategic or national levels. The distinction between economic, financial, environmental, and social impacts is also difficult to separate in reality [69]. Furthermore, while some of the expected outcomes may be visible in the short-term, many others are only likely to become apparent in the longer-term; assessment of the latter is necessarily more speculative. The macro-level evaluation of Dem@Care therefore presents a greater challenge than the previous micro-level assessment. However, many of the societal outcomes build upon the successful attainment of outcomes at the personal (micro) level, in combination with those impacts evident at a meso-level (community, organisation, networks, and industry sectors). This is the approach that will be used in this societal impact assessment in an attempt to evaluate the wider economic and societal benefits that may accrue from the Dem@Care project.

3.4.1 Economic impact

Wide deployment of ICT solutions are at least partly based on expectations of cost reductions or cost avoidance, more easily controlled resource allocation, service quality improvements, and the enhancement of revenue streams [70]. Some of the economic impacts that may be attributed to the use of the Dem@Care system, for example, would be:

– The potential to improve early diagnosis through more widespread screening practice using the Dem@Lab system. Savings may be as much as a decrease of 30% in outpatient care costs [71]

– The reduction in staff costs, along with improvements in quality of life for other residents, through early detection BPSD using the Dem@Nursing system.

– The prolongation of autonomous home living for a PWD using the Dem@Home system, and the resulting revenue maintenance or enhancement that may be possible for carers if they are in a position to return to work.

Economic impacts can also be both real and perceived and a mixed-method approach will be used to gather the data needed for this evaluation. At an individual level, in additional to the personal impacts described above, informal carers will be asked to give an account of the number of care hours they spend and their perception of how this has changed as a result of using the Dem@Care system. This data will also provide an indirect commentary on carer quality of life improvement. At a meso-level, economic modelling would be required in order to quantify the costs generated by organisational change, which is outside the scope of this stakeholder review. Instead, systemic indicators will be identified that illustrate the cost of underemployment due to caregiving and where possible, the cost of conventional care alternatives so that Dem@Care costs can be compared to feasible alternatives. This data will be important in order to convince stakeholders of the benefits of adopting the Dem@Care system.

3.4.2   Social impact

The wider social impacts of the Dem@Care system will centre on the inclusion of the PwD in the community and increasing the awareness and understanding of dementia in the general public. For example, the Dem@Care system has the potential to maintain PwD as active citizens for longer, avoiding their isolation in their own homes or in nursing homes, and a more thorough understanding of the Behavioural and Psychological Symptoms of Dementia (BPSD) can facilitate reduced stigma by recognising that PwD have various and highly individual degrees of difficulties, some which that they share with people who do not have a dementia diagnosis. Therefore, impacts in the domain will focus on increased social contact, increased tolerance and understanding of other people, group identity, interpersonal skills, and community and organisational impacts.

However, there is a long pathway between applied research and the realisation of the social impacts resulting from that research. The latter can often only be identified following a longer deployment of the Dem@Care than is available here and some time after research results have been disseminated. As a result, proxy indicators of social impact will be required, such as analysing the social response to dissemination activities. It should be noted that this dissemination does not assume a purely academic or technical audience, but one which encompasses local health authorities, general practices, hospitals, for-profit and non-profit advisory agents, professional organisations, and community groups. For the purposes of this evaluation, we will focus on those social impacts that are somehow visible as behavioural intentions and/or behavioural change; for example, acknowledgement from policy and decision makers that Dem@Care has a place in revised or new dementia healthcare policies.

The expected socio-economic outcomes and the assessment plan to evaluate these outcomes are presented in Table 5 below. Data will be required from all stakeholders in order to complete this assessment. It is expected that most of the input required will be collected during the three Dem@Care pilot studies and during the end-of-project interviews.

Table 5 Matrix for assessing the socio-economic impact of Dem@Care

OUTCOME	INDICATORS (Time frame)	MEASUREMENT TOOLS / EXPECTED RESULTS	CONTRIBUTING ACTIVITIES

Alleviate medical costs from families	– Dem@Care is a cost efficient way of providing effective care (MT)
	
	– The cost of Dem@Care is considered to be appropriate for the functionality it provides (MT)
	
	– Improved economic position of carer (MT)
	
	– Reduced nursing care costs (LT)
		– Successful attainment of the personal outcomes for the PwD and their informal carer
		
		– The outcomes expected in the intermediate time-frame will be examined using a combination of questionnaires and semi-structured interviews to establish:
		
		  o Reduction care at home for informal carers that releases time for these individuals and facilitates the maintenance or (re)commencement of activities that improve the economic position of the household
		  o Usefulness of Dem@Care in relation to the expected cost
		  o User acceptance and integration in daily life and workflow.
		– It will not be possible to objectively measure the LT outcomes over the course of this project, as this would require a longer period of deployment of the final version of the system. Likely savings will be extrapolated from the user acceptance and integration of the Dem@Care system in daily life and workflow and the degree to which personal outcomes have been achieved for each of the stakeholder groups.
			– Comprehensive Dem@Home solution
			
			– Data collection and pattern comparison over a long period of time for meaningful results that demonstrate:
			
			  o Improved skills and functioning in the domains of interest to the PwD
			
			  o Accurate detection of these skills and/or related problems and demonstration of how these change over time.
			
			– Establishment of likely costs for the Dem@Care system (WP9) including the ability to derive costs for different combinations of exploitable components (as per the toolbox approach)

Alleviate medical costs from national healthcare systems	– PwD stays at home for longer (LT)
	
	– Reduce unnecessary hospitalisation of PwD (LT)
	
	– Reduce length of time a PwD spends in formal nursing care (LT)
		– Successful attainment of the personal outcomes for the PwD and their informal carer
		
		– Interviews with each of the relevant stakeholders
		
		– Successful attainment of the personal outcomes for the Clinician, specifically:
		
		  o Sense of improvement over existing assessment methods
			– Comprehensive suite of Dem@Care systems for the Lab, Nursing Home, and Home environments
			
			– Data collection and pattern comparison over a long period of time to demonstrate:
			
			  o Improved skills and functioning in the domains of interest to the PwD

OUTCOME	INDICATORS (Time frame)	MEASUREMENT TOOLS / EXPECTED RESULTS	CONTRIBUTING ACTIVITIES
Alleviate medical costs from national healthcare systems **(continued)**	– Clinicians help a larger number of people (MT)	o Clinician acceptance of the Dem@Care system and integration into their assessment and care routines	o Accurate detection of these skills and/or related problems and demonstration of how these change over time. – Data collection and diagnostic analysis across a large number of @Lab participants to deliver meaningful results that demonstrate: o Increase in diagnostic accuracy – Decrease in time needed to perform the diagnosis
Commercial Impact	– Marketability of the Dem@Care system (LT)	– Number of exploitable components – Associated market value – End-user satisfaction levels – Solution deployment delivered in a range of different environments	– Adoption of a toolbox approach to the deployment of the Dem@Care system – Identification of a range of exploitable components – Stakeholder co-design of system requirements in a range of pilot settings (@Lab, @NH, @Home) – Pilot evaluations in a range of settings
More socially inclusive Dementia-friendly societies	– Increased social interaction for PwD (MT) – Reduction in carer burden such that carers return to their usual place and role in society (MT) – Contribution to more and better knowledge of dementia in caregivers, families, and more generally in the population (MT) – Reduced social disturbance by PwD with BPSD (MT)	– Successful attainment of the personal outcomes for the PwD and their informal carer. The measures for each of these items are included in the personal impact section above. – User acceptance and integration in daily life and workflow – Interviews with each of the relevant stakeholders to examine the increase in dementia-related knowledge as a result of using the Dem@Care system. – Systematic observations of social disturbance by PwD – Dissemination of research results from all pilot sites	– Comprehensive Dem@Home and Dem@Nursing solutions – Data collection over an extended period of time @NH and @Home – Wide-ranging and impactful dissemination of results

OUTCOME	INDICATORS (Time frame)	MEASUREMENT TOOLS / EXPECTED RESULTS	CONTRIBUTING ACTIVITIES
Increased awareness of Dementia	– Increased awareness at the political level (MT) – Increased awareness at the policy level (MT) – Increased awareness in the healthcare community (MT) – Increased awareness in the scientific community (MT) – Increased awareness in the general public (MT)	– Metrics regarding dissemination at the political level (what, how many, reach, etc.) – Metrics regarding dissemination to policy makers (includes politicians, healthcare professionals, experts) – Metrics regarding dissemination to a healthcare audience (publications, conference presentations, demonstrations, etc.) – Metrics regarding dissemination to a scientific (academic and technical) audience (publications, conference presentations, demonstrations, etc.) – Metrics regarding press releases and dissemination to the general public	– Stakeholder co-design sessions – Recruitment activities at each pilot site – Completion of three pilot evaluations at each site – Stakeholder interviews carried out as part of the pilot evaluations and as part of the evaluation activities for this report – Dissemination activities of all partners

Note: ST, short-term; MT, medium-term; LT, long-term.

3.5   The scientific impact of Dem@Care

There are three domains in which Dem@Care is expected to advance the state-of the art: technology, clinical practice, and the ethical use of technology and healthcare.

3.5.1   Advancing the technical state-of-the-art

From a technical perspective, Dem@Care will expand upon current State-of-the-Art multi-sensing and lifelogging technologies and knowledge strategies. Multiple sensors (physiological, life-style monitoring, and audio) will be deployed to obtain a richer description of the daily life, activities, and behavioural patterns of PwD. In order to achieve this goal:

- several advances in challenging problems in visual sensing will be made

- state-of-the-Art sensor fusion technologies will be enriched with spatio-temporal reasoning in order to deal with noisy and incomplete data from real-world environments

- Data mining of multi-sensor data will produce higher level interpretations of activities and events already extracted by the corresponding processing algorithms

- Unified context and uncertainty representation and scalable hybrid reasoning will be used to interpret the multi-sensor outputs in a meaningful and robust manner

- Dem@Care will provide improved remote management and care solutions for PwD and their caregivers, with dynamically evolving personal feedback, which aims to provide accurate and meaningful feedback with minimal interference in the daily lives of PwD.

3.5.2   Advancing the clinical state-of-the-art

From a clinical practice perspective, current questionnaire-based assessment approaches tend to introduce a high level of subjectivity, while lacking the comprehensive view of the person's life and status that only continuous monitoring can provide. Given that standard diagnostic scales also fail to fully capture the complexity of dementia, Dem@Care aims to provide a novel and holistic solution for the clinical management of dementia that includes:

- A professional loop that provides objective observations regarding the health progression of the PwD and medication effectiveness, warns professionals about unfavourable trends, and supports preventative care decision-making and the timely updating of care-plans for the PwD.

- A loop for PwD and their informal caregivers that monitors and assesses their health status by integrating the information from multiple wearable and ambient sensors, enables time-evolving context-sensitive profiling to support reactive and proactive care, and provides personalised supportive feedback.

3.5.3   Advancing the ethical state-of-the-art

The issue of ethics is something that is of major concern when it comes to using technology in healthcare. Ethical dilemmas arise on a daily basis for those providing care for people with dementia. The way in which these dilemmas are approached will have significant impact on the lives of people with dementia and their carers. Good, ethical care recognises the value of the person with dementia. It aims to promote the well-being and autonomy of the person with dementia. At the same time, it pays attention to the interests of carers who provide so much of the day-to-day support. How things are done, in a way that people with dementia feel that they are valued individuals, will often be far more important than the particular structure or format of service (see D2.1, Ethical Literature Review and D2.5, Ethical Guidelines for a comprehensive discussion of ethical requirements).

From an ethical perspective, the main outcome will be further insight into a number of ethical considerations that deserve attention:

- How do we balance the need to intervene earlier in the course of a person's dementia with making sure that people do not feel coerced into accepting interventions that they do not want and may not need?

- Relying on carers or family members to give consent is sometimes the only way to proceed in situations where the PwD does not have the capacity to do so, but in the absence of any ethical framework that is accessible to carers and service providers. How do we ensure that whoever makes the ultimate decision is conscious of the responsibility and the ethical dilemmas involved?

- How do we determine who benefits from a specific intervention, and how should we negotiate between the respective needs and rights of people with dementia, and those of informal carers?

The expected scientific outcomes and the assessment plan to evaluate these outcomes are presented in Table 6 below. Data will be required from all Dem@Care partners and all stakeholders in order to complete this assessment. Much of the data will come from analysing the accuracy of Dem@Care results in the three pilot studies, along with end-user acceptability and usability findings. The remaining data will be derived from the spread of dissemination of results to wider stakeholder groups.

Table 6 Matrix for assessing the scientific impact of Dem@Care in technical, clinical, and ethical domains

OUTCOME	INDICATORS (Time frame)	MEASUREMENT	CONTRIBUTING ACTIVITIES

Contributions to state of the art (SOA) technical knowledge	– New/Original knowledge structures and reasoning methods (ST)
	
	– New rules and associations (ST)
	
	– New algorithms for processing visual information (ST).
	
	– New methods of characterising emotional, functional, and psychological state of an individual from audio data (ST)
	
	– Improved accuracy for ADL recognition (ST)
	
	– Behaviour profiling and interpretation in a medical context (ST)
	
	– Behaviour profiling and interpretation in other contexts (LT)
	
	– New data mining techniques for continuous scanning for new patterns and correlations between PwD difficulties and the events that cause them (LT)
		– Measurement of the technical contribution is generally reflected in an increased accuracy in event detection on the given data.
		
		  o A baseline is established (generally a widely-accepted state-of-the-art method) on a particular dataset (which could be a domain standard or generated for the task).
		
		  o Developments to the system are judged by their difference to the baseline.
		
		  o For example, for ADL recognition, accurate detection and recognition of ADLs in benchmark datasets and in Dem@Care datasets and comparison with other ADL detection/recognition methods (SoA)
		
		– Metrics regarding publications in scientific journals and at conferences (what, how many, reach, etc.)
		
		– In the case of Dem@Care, further evaluation of the systems is given by their "acceptability" to the PwD, carers, family, clinicians, etc. This can be subjective, and thus might not typically be considered a technical measurement. Nevertheless, such evaluations are important to determine the utility and long-term viability of systems in real-world applications.
		
		– Evidence of the application of the algorithms for visual recognition of objects and behaviours from the Dem@Care system to other environments.
		
		–
			– Development of knowledge structures (ontologies) for the representation of the information modalities required for the high-level interpretation of the behaviour and health status of the PwD (WP5)
			
			– Activity detection – although this has received limited attention, it is necessary for real – world implementations of activity recognition algorithms.
			
			  o Development of several versions of activity detection algorithms, which, combined with activity recognition, lead to highly accurate recognition rates (WP5)
			
			  o Real-time complex activity recognition based on localisation and elementary states. (WP5)
			
			– Context-based fusion for complex activity recognition and interpretation (WP5 – HAR component).
			
			  o Fusion of objects and locations detected from wearable camera
			
			  o Developed new methods for fusing information collected by multiple sensors and complementary modalities (e.g. static and wearable cameras), and higher level interpretation based on clinical and patient profile knowledge
			
			  o Knowledge-driven fusion of heterogeneous data retrieved from multiple sources in order to handle noise, conflicts or inaccurate temporal correlations
			
			– New software components for interacting with clinicians, care staff, informal carers, and PwD (WP6)

OUTCOME	INDICATORS (Time frame)	MEASUREMENT	CONTRIBUTING ACTIVITIES

Contributions to state of the art (SOA) technical knowledge
 	
(continued)
			– Innovation has also been driven by the application of existing technology to a new domain, specifically that of measuring activities of daily living of people with dementia (PwD).
			
			  o Increase in the accuracy and range of detected events across data media and sensors (WP3)
			
			  o Smart Networks (WP3): A set of ambient sensors (motion and presence sensors, binary contact sensors) are used to generate knowledge of the PwD's daily activities and movements within their home. This data can be fused with other sensor data to infer knowledge about activities and events within the home environment.
			
			– Lifelogging combines longitudinal data to allow the examination of data over long lengths of time, in order to identify and visualise trends in the activity and behaviour of the PwD (WP4).
			
			– Long term behavioural/lifestyle/activity profiling can be achieved through the deployment of activity detection and recognition over a long time period.
			
			– Long-term data collection to facilitate the development of new data mining techniques.

Contributions to SOA clinical knowledge	– Availability of multi-modal databases to facilitate medical research and benchmarking (MT) – Increased ability to detect unusual activities (MT)	– Acceptance and usability of Dem@Care system by all end-user groups – Metrics regarding publications in scientific journals and at conferences (what, how many, reach, etc.)	– Enable diagnosis and autonomy assessment at Lab (WP5) – Continuous collection of data from sensors in diagnostic rooms will build a valuable corpus of knowledge of individual performance of directed and semi-directed activities, stratified along multiple clinical, cognitive, and behavioural scales. This will progressively improve the accuracy of assessment of the cognitive decline of PwD and persons with a diagnosis of MCI.

OUTCOME	INDICATORS (Time frame)	MEASUREMENT	CONTRIBUTING ACTIVITIES
	– Increased ability to detect emotional, functional, and psychological state of the PwD (MT) – Increased accuracy in predicting dementia progression (LT) – More timely diagnosis of dementia (LT) – More timely support for PwD and their carers (LT)		– Extensive multi-sensor data collection has taken place at the Nice University Hospital. This has been complemented by multi-sensor data collection at the GAADRD in Thessaloniki. – – Objective feedback about problems in each of the five domains will enable clinicians to schedule more timely follow-up meetings, and for carers in nursing homes to have complementary supporting information about each PwD for follow-up and planning meetings.
Contributions SOA ethical knowledge	– Increased awareness of the ethical issues related to the use of ambient and wearable technologies in Lab, Nursing Home, and Home settings (ST) – Increased awareness of the ethical issues related to long-term research with a dementia population (ST)	– Metrics regarding dissemination of ethical guidelines and discussion of the specific ethical issues that arose over the course of this project	– Extensive ethical literature review (WP2) – Preparation of ethical guidelines (WP2) – Ethical monitoring and review process (ALL)

Note: ST, short-term; MT, medium-term; LT, long-term.

4   The Evaluation of the First Dem@Care Pilot

The initial Dem@Care pilot evaluation assessed the first iteration of the Dem@Care system and as such, it would not have been expected that this early system would meet many of the final Dem@Care outcomes. However, the findings of this evaluation offer useful insights into the progress made towards achieving these outcomes, so they provide useful lessons to be learnt for the remainder of the programme. A detailed presentation of the assessment of this first pilot is presented in the D8.3 Initial Pilot Evaluation report. A brief summary of the most relevant findings are presented here.

4.1   Outcomes for PwD and for informal caregivers

The majority of the useful feedback related to personal outcomes for the PwD and their informal caregiver was obtained from the evaluation of the first @Nursing Home and @Home pilots. In general:

- Sleep data: patterns corresponded well with research observations (accuracy) in the nursing home, and the added value of more detailed sensor observations was evident. Data analysis was not possible using Dem@Home but the sleep data capture rate was 83% and the sensor feedback screens could be used to discuss feedback. High levels of acceptability were also found for the Gear4 sensor.

- Physical Activity: The DTI-2 sensor was less well received; although comfortable for some, it was ill-fitting for others. Data capture success rates were 38% @Home and synchronisation was identified as very problematic. Although the PwD typically disconnects the device from the PC and places it on their arm each day, some element of help is required from the carer to ensure that it is adequately charged and synchronised each evening and data tended to be lost when the carer was ill or unavailable.

- IADLs: Asus data was collected successfully @NH but no participants have consented to use this sensor to data @Home. Wearable video data was successfully collected @Home, but the analysis of this data was not a focus for pilot 1 so the accuracy and usefulness of this data has yet to be established.

- Social Interaction and Mood were not assessed as part of this pilot, so the accuracy and usefulness of this data has yet to be established.

A number of key issues were encountered that unless addressed will limit the acceptability and usability of the system for these particular groups.

- Usability:
  - Sleep sensor: too easy to touch, and interfere with; it was reported to be difficult to use by formal care staff and by PWD and informal carers; it was generally used more easily by people comfortable with iphone/ipad technology; interaction was required to start and stop the device. The issues raised by people without a dementia diagnosis reinforces the importance of minimising the interaction needed with the sensors for the PwD

- o DTI-2: uncomfortable and does not fit smaller wrists, is difficult to attach, and needs to be charged overnight which prevents data collection at night.

- o Carers indicated that all wearable sensors must be fiddle-proof and must not interfere with any health and safety sensors also worn by PwD (e.g. panic bracelets)

- o The WIMU sensors may have provided information on particular movements or actions that would not be detected by DTI-2 due to its lower granularity. They lack of comfort and general low acceptability of these devices, both in this pilot test and in the feedback from the @Lab pilot, combined with the fact that the DTI-2 sensor can be used to provide much longer periods of measurement than WIMU, have resulted in the removal of the WIMU from the @Home protocol.

- Acceptance:

  - o Recruitment was very difficult in the @Home environment given the relative immaturity of the Dem@Care system and a general wariness with regard to technology in the population of PwD/Carers approached. Many described themselves as technophobic, allergic to computers, or completely uninterested. Some were open to trying as long as no new learning was required and that it didn't cause them additional stress and anxiety.

  - o Many stay-at-home carers felt that they did not need the technology as they were there, they could manage fine, and they 'knew what was going on' anyway. These perceptions can be inaccurate and we need to consider how to challenge these without causing the carer undue stress.

  - o Almost all carers indicated that they had 'enough going-on' and that they were not interested in new hassles, new learning, or interruptions during their day. The current levels of new learning and required. technical knowledge are sufficiently high as to make recruitment of new lead user dyads very difficult

- Ethical concerns:

  - o The technology caused anxiety in PwD with limited or no experience with technology – this issue was evident in all environments.

  - o Testing in the DCU flat was shown to be a critical stepping stone needed before @Home deployment to ensure stability of sensors and system. PwD cannot be the initial end-user of any new functionality given the stress and confusion caused for both PwD and their caregivers when problems arise.

  - o Potential @Home participants have been very reluctant to engage with the ambient video sensors despite the adoption of blind-sensing approaches. Most interest comes from informal carers who do not live in the same house as the PwD, but the interest is in accessing video footage as a surveillance tool (e.g. to see where PwD might be hiding items), which is contrary to the ethics of the programme.

  - o Assuming that sensors can operate automatically and without specific intervention by the PwD or the carer, there would be a requirement to easily be

able to stop or pause Asus recording if there was a visitor to the home who had not provided their consent.

In general, open and exploratory attitudes to technology are required so that 'pilot' versions of the Dem@Care system can be tested with all of their inherent instability. In addition, lead user anxiety was high during the initial deployment of the sensors in the home environment. It helped them to know that the data was considered 'training' data and that it would only be used to determine if the sensors were working correctly; it would not feed into the full Dem@Care system for that dyad. As a result, a training period needs to be built into deployments to future @Home dyads.

4.2   Outcomes for clinicians and formal care-givers

Overall, the evaluation of the first pilot demonstrated promising and useful results. Video sensor accuracy of 79% and audio accuracy ranging from 80% (control versus MCI) to 87% (control versus AD) were found. The data collected @Lab has been extensively studied in order to determine the usefulness and relevance in clinical practice. The correlation studies showed that the data is associated with cognitive decline and autonomy level, both assessment targets in particular in the @Lab setting. The classification results validated the sensor output and provided the clinician with meaningful and reliable information about a patient's functional state. Protocol tasks were validated and some improvements suggested for future pilots (e.g. gait analysis, repeating sentences task). The system was also able to deliver the clinician with an immediate output after recording sessions. That said, a number of key issues were encountered that need to be resolved in order to fully achieve expected outcomes:

- Although the clinician output was valid, it was cumbersome and feedback needs to be tailored for their specific needs

- The maturity of the gait analysis functionality did not allow for the prediction of assessment scores in this area

- Significant technical problems arose which extended the evaluation period, causing fatigue and nervousness. Although this is to be expected from a pilot, it highlights the difficulty of deploying the early versions of the Dem@Care system to less structured and supported environments (e.g. @NH and @Home).

4.3   General findings

A range of technical and practical issues were also encountered across the environments that will need to be addressed. Again, this is not unsurprising given that an early Dem@Care prototype was evaluated and the pilot studies are a means of uncovering these kinds of problems. However, this does make early iterations of the system difficult to deploy in unstructured environments such as @NH and @Home.

- The installation process is cumbersome and difficult to follow. The system cannot be installed by a skilled technician; support was required by various developers is required.

- The system has many components that require many actions to function, yet the target audience for Dem@Care is by tradition 'low tech'.

- Sensors must be neat, unobtrusive, and generally more elegant, and require fewer and smaller computers to operate successfully.

- Synchronisation of sensors is particularly problematic especially in the home environment. Sensors must not require any technical knowledge on the part of the PwD or the carer.

- GUIs should be more user-friendly, integrated, and provide flexible problem summaries.

- The data transfer process is too complex, error prone, slow, and CPU intensive, while the data itself requires a lot of space.

- Data fusion was not available so the visualisation of multi-sensor data was not possible in this pilot.

These findings illustrate the importance of ensuring that the Dem@Care system, including all sensors, is very simple to operate. It is important that the system is stable and robust in order to facilitate familiarisation and learning. The currently low acceptability and usability ratings indicate that the system needs to be modified in line with end-user feedback, that better end-user training and/or education should be provided. If acceptability and usability of the Dem@Care system remain low, the system will have limited use and it will be less meaningful to evaluate personal impact. Therefore, Dem@Care needs to be fully integrated in the lives of end users so that the personal impact can be truly evaluated objectively. Furthermore, If the system is better integrated into the lives of the end-user, its benefits will become increasingly obvious; increasing the independence of the PwD, allowing for better remote care, relieving caregiver burden, with significant positive socio-economic impacts. On the other hand, low usability and acceptability will have no true societal impact. In reality, an intermediate period will occur where benefits and disadvantages of the system will become apparent during deployment, which will require continuous feedback and development loops in order to improve the Dem@Care system and ensure its positive impact on individual stakeholders and on society.

5 Conclusions

The number of people with dementia in Europe is predicted to be around 10 million people in 2010. The total costs, including informal care, for caring for people with dementia is estimated to exceed 100 billion € for Europe. The number of people with dementia is expected to increase approximately 40% to around 14 million people in 2030. Furthermore, the old age dependency, i.e., the ratio of elderly people versus the working population is expected to double in the next fifty years throughout Europe. Cost-effective solutions are therefore crucial to improve or even maintain the current quality of care for people with dementia.

In this document we have presented a methodology and plan to assess the personal, societal, and scientific impacts of the Dem@Care system across all pilot sites. In doing so, expected outcomes, outcome indicators, measurement tools, and contributing activities have been identified for all anticipated areas of impact. The report also presents several interesting and important findings when the results of the first Dem@Care pilot are considered in relation to these areas of impact.

A full impact assessment for the final Dem@Care system will be presented in our subsequent deliverable (D2.8) at the end of the project. In the interim, the protocols for the remaining pilot evaluations will be reviewed to ensure that all measurements needed for the successful completion of the impact assessment are included therein. Where they are not, additional measures will be added. Confirmation of the final set of expected and delivered functional and non-functional requirements will inform the completion of the interview and focus group questions, and of the impact assessment questionnaires. Finally, concurrent work in WP9 (Dissemination and Exploitation) will determine a clear strategic direction for the exploitation of the Dem@Care system and this will provide additional context within which the final impact assessment will be carried out.

6 References

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