# D2.8

# Stakeholder impact v2

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

**Dem@Care - FP7-288199**

eHealth
Better Healtcare for Europe

SEVENTH FRAMEWORK PROGRAMME

European Commission
Information Society and Media

# Deliverable Information

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|---|---|---|
| **Project Ref. No.** | | FP7-288199 |
| **Project Acronym** | | Dem@Care |
| **Project Full Title** | | Dementia Ambient Care: Multi-Sensing Monitoring for Intelligence Remote Management and Decision Support |
| **Dissemination level:** | | Public |
| **Contractual date of delivery:** | | Month 47, September 2015 |
| **Actual date of delivery:** | | Month 48, October 2015 |
| **Deliverable No.** | | D2.8 |
| **Deliverable Title** | | Stakeholder impact v2 |
| **Type:** | | Report |
| **Approval Status:** | | Draft |
| **Version:** | | 9 |
| **Number of pages:** | | 63 |
| **WP:** | | WP2 |
| **Task:** | | T2.5 |
| **WP/Task responsible:** | | DCU |
| **Other contributors:** | | Airbus, Certh, CHUN, Inria, LTU, PENB, UBX, Vispera |
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| **Abstract**<br>**(for dissemination)** | | This deliverable is the final output from task 2.5. It presents an assessment of 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 the results from the three Dem@Care pilot studies and expert reviews. |

# Version Log

| Version | Date | Change | Author |
|---|---|---|---|
| V1 | 14/07/2015 | Document outline | Louise Hopper (DCU) |
| V2 | 29/09/2015 | Amalgamation of all of the outcome-supporting evidence from the clinical and technical partners | Louise Hopper (DCU) with input from all partners |
| V3 | 10/10/2015 | Inclusion of summary contextual information from the final exploitation report | Louise Hopper (DCU) with input from WP9 team |
| V4 | 26/10/2015 | Preparation of initial full draft for review | Louise Hopper (DCU) |
| V5 | 28/10/2015 | Incorporation of final results and review feedback in preparation for internal review | Louise Hopper (DCU) |
| V6 | 09/11/2015 | Address feedback from internal review | Louise Hopper (DCU) |
| V7 | 12/11/2015 | Incorporate additional results from Thessaloniki pilots | Thanos Stavropoulos, Georgios Meditskos (CERTH) |
| V8 | 12/11/2015 | Prepare final version for submission | Louise Hopper (DCU) |
| V9 | 14/01/2016 | Updated to address EU Reviewer comments | Louise Hopper (DCU) |

# Executive Summary

This deliverable presents an assessment of 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, technical and ethical state-of-the-art. It is based on an understanding of current care management practices, the role of ICT solutions in dementia care, and on the results of the @Lab, @Nursing Home, and @Home pilot studies.

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 facilitated a single impact evaluation strategy.

Dem@Care has been found to have a positive impact for people with dementia. Evidence is presented that demonstrates its ability to enable increased independence, to provide a sense of improvement in the five key domains addressed by the system (sleep, physical activity, social interaction, activities of daily living, and mood), and a sense of improvement in their subjective quality of life. It does so through the use of personalised adaptive feedback and by supporting and monitoring the effectiveness of individualised interventions. It has also been shown that the improvements for the person with dementia translate into a sense of improvement for their informal caregivers, and increased independence for some of these caregivers. The level of independence achieved is dependent on the stage of dementia that they are caring for. However, the @Home pilots relied on substantial support from clinicians, therapists, and research staff and the possibility that this, rather than the Dem@Care system itself, is influencing the well-being of the participants cannot be discounted. Further trials are required to differentiate the impact of Dem@Care from that of the surrounding support for people with dementia and their informal caregivers. Nevertheless, preliminary results are in a good direction.

Evidence is also presented that demonstrates that clinicians and formal care staff benefit from improved assessment and diagnostic procedures, enhanced ability to make differential diagnosis, and more timely identification of functional, behavioural, and emotional pattern changes. Early diagnosis is an important for effective provision of dementia care with the potential to reduce care costs for national health systems. Achieving a better understanding of behavioural and psychological systems associated with dementia enables nursing home staff to develop and evaluate person-centred interventions and to better manage the care of the person with dementia such that the emotional and social disturbances of these symptoms can be better managed.

From a technical perspective, Dem@Care has advanced the state-of-the-art through its use of novel visual sensing algorithms, highly accurate real-time event detection and people

tracking, intelligent machine learning and dynamic model adaptation, advanced audio sensing, novel context-aware multi-sensor, intelligent event-driven feedback mechanisms, and adaptive visualisations of daily activities and personalised alerts, thus enabling scheduled problem checks and other automated interventions. Finally, using state-of-the-art protocols for security, extensibility and modularity, the Dem@Care platform enables secure integration with the most recent sensors and offers adaptability to each person's needs in terms of comfort, clinical needs, and areas of interest.

Although it is difficult to evaluate the longer-term economic and societal outcomes, it is suggested that the successful attainment of personal impacts for each of the stakeholder groups will, over time, lead to a reduction in healthcare costs, less social isolation for the person with dementia and for their informal carers, and more socially inclusive dementia-aware and dementia-friendly societies. Finally, Dem@Care is shown to have contributed to the advancement of the technical, clinical, and ethical management of dementia care through its innovative use of ICT solutions.

## Abbreviations and Acronyms

| | |
|---|---|
| **@Home** | Pilot in the home environment (Ireland, Greece) |
| **@Lab** | Pilot in the lab environment (France, Greece) |
| **@NH** | Pilot in the nursing home environment (Sweden, France) |
| **AAL** | Ambient Assistive Living |
| **AD** | Alzheimer Disease |
| **ADL** | Activities of Daily Living |
| **BAI** | Beck Anxiety Inventory |
| **BDI** | Beck Depression Inventory |
| **BPSD** | Behavioural and Psychological Symptoms of Dementia |
| **CERTH** | Centre for Research & Technology Hellas |
| **CHUN** | University of Nice Hospital |
| **CSP** | Case Study Participant |
| **DCU** | Dublin City University |
| **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 |
| **ECG** | Electrocardiography |
| **FRSSD** | Functional Rating Scale for Symptoms of Dementia |
| **FUCAS** | Functional Cognitive Assessment Scale |
| **GDP** | Gross Domestic Product |
| **GDS** | Geriatric Depression Scale |
| **GP** | General Practitioner (primary care clinician) |
| **IADL** | Instrumental Activities of Daily Living |
| **ICT** | Information and Computer Technology |
| **LTU** | Luleå University of Technology |
| **MMSE** | Mini Mental State Exam |
| **MoCA** | Montreal Cognitive Assessment |
| **NPI** | Neuropsychiatric Inventory (NH – Nursing Home) |
| **OECD** | Organisation of Economic Cooperation and Development |
| **PSQI** | Pittsburgh Sleep Quality Index |
| **PwD** | Person with dementia |
| **QoL** | Quality of Life |
| **SOA** | State-of-the-art |

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| **TEA** | Test of Everyday Attention |
| **USD** | US Dollars |

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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 were 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 [1].

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].

With the prevalence of aging populations, the risk for cognitive impairment leading to dementia is increasing, and 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, 6]. Today, more 9.9 million people in Europe, are living with dementia [7] accounting for over 28% of the total number of people with dementia worldwide. Around half of all people with dementia need personal care; the others will develop such needs over time. Dementia is thus significantly affecting every health system in the world and they are struggling to live up to the challenge of effective care delivery and management of dementia primarily due to the cost of providing care and support and the absence of a disease-modifying treatment. The total estimated costs of dementia in 2010 were $604 billion worldwide (or 1% of the aggregated worldwide GDP) [8] and $135.04

billion in the EU [7]. If dementia was a country, it would rank between Turkey and Indonesia and be the world's 18th largest economy [6].

Health care policies in many countries aim to enable people with dementia 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 [9], but it places a higher demand on formal care services and informal care in the middle phase of dementia. Two thirds of people with dementia 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 people with dementia in Europe are currently receiving unpaid care [10]. But informal carers can experience high levels of stress, depression, social isolation and physical health problems [11], 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 [12, 13] and increase the pressure on formal and long-term care facilities. This highlights the importance of using formal home-based services to support the person with dementia and also their families.

There is a pressing need for innovative dementia care solutions that enhance the quality of life for people with dementia, decrease caregiver burden, and reduce care costs. For these reasons, early detection, treatment and management of dementia are now considered priority research areas. Key challenges will be to develop ways of assisting the person with dementia to remain independent, autonomous, and capable of living well at home for longer, as well as sustaining their social networks and enabling them to live as a valued member of their family and their wider community.

The overall goal of the Dem@Care project is to provide an integrated remote care and management solution for people with dementia by bringing together leading experts in dementia, physiological sensor data modelling, video and audio analysis, life-logging, lifestyle analysis, data mining and fusion, knowledge modelling and semantic inference. The Dem@Care project is a multi-disciplinary, multi-partner research endeavour that aspires to contribute to the innovative and cost-effective provision of dementia care.

This report, the final deliverable from Task 2.5, assesses and measures the impact that Dem@Care has on many stakeholders involved in the care of people with dementia. It is organised as follows. Section 1 continues with a short review of the current dementia care environment and the role that ICT solutions can play with regard to the provision of dementia care. It presents a description of the detailed goals of the Dem@Care system in relation to diagnosis and care and it concludes with a summary of the evaluation methodology; this has previously been described in detail in the First Stakeholder Report (D2.7). Section 2 assesses the personal impact for the person with dementia, the informal caregiver, clinicians and formal care staff. Section 3 evaluates the broader economic and social impacts for health and social care provision, while Section 4 considers the contribution Dem@Care has made to the furthering of clinical, technical, and ethical, state-of-the-art research. Finally, our conclusions are presented in Section 5.

## 1.1 The current dementia care environment

Dementia is characterised by progressive deterioration of cognitive, emotional, and functional abilities. It is the leading chronic disease contributor to disability, and, particularly, to dependence among older people worldwide. While older people can often cope well and remain reasonably independent even with marked physical disability, the onset of cognitive impairment quickly compromises their ability to carry out complex but essential tasks and then even to meet their basic personal care needs. The need for support from a caregiver often starts early in the dementia journey, intensifies as the illness progresses over time, and continues until death [6].

In High Income Countries, governments are struggling to find ways to sustain the high levels of social protection that are the cornerstone of their welfare states (entitlement to pensions, benefits, and comprehensive health and social care) in the context of stagnant economic growth, ageing populations, and rapidly increasing demand for cost-intensive services. The OECD predicts that spending on long-term care will double or even triple between now and 2050, with prices rising due to demand for better quality and more responsive, patient-oriented social-care systems. The credit rating agency Standard & Poor's now considers global ageing to be a significant threat to economic stability, since without changes to age-related public spending, sovereign debt could become unsustainable [6].

### Providing care for mild to moderate dementia

Dementias are progressive, with a gradual increase in loss of cognitive and functional capacities. Two thirds of people with dementia 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, people with dementia 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 people with dementia in Europe are currently receiving unpaid care [10]. 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 [9]. 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 people with dementia 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 [11, 14, 15].

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 [16]; 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 [16].

Health care policies in many countries aim to enable people with dementia 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 [17]. Unfortunately, research has revealed that people with dementia 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 [16, 18]. This can put increasing pressure on people with dementia and their carers which might lead to admission to a residential home simply because the appropriate support is not in place [19]. This highlights the importance of developing formal home-based services to support people with dementia and their families.

### Behavioural and Psychological Symptoms of Dementia

A relationship has been found between the cost of dementia care and the presence of behavioural and psychological symptoms in dementia (BPSD) [20]. BPSD are common. They affect more than 90% of people with dementia at some point during the course of the disease [21-23], and they present a challenge in terms of providing effective care and also from an economic perspective. The complexity of assessing, understanding, and perceiving the underlying problems from the perspective of the person with dementia adds to this challenge as it requires the collective competence of multi-professional teams. At the same time, understanding the medical and care needs and what actually supports the well-being of the person with dementia is one of the most important aspects of a value-based personalized care system. Some research evidence suggests that training health personnel in the use of structured assessments using validated instruments such as the Neuropsychiatric Inventory Questionnaire, nursing home version, NPI-NH [24], can improve the quality of care. The NPI-NH is based on structured proxy assessments of the different dimensions of BPSD, but the quality of the assessment is very much dependent of the competence on the health personnel administering it.

In Sweden a model for using the NPI-NH as a tool in the care of BPSD, the BPSD register (**www.bpsd.se**), has been developed. This tool aims to improve quality of care and to achieve a national standard of care throughout Sweden. The register has a clear structure that relies on outlining the frequency and severity of BPSD using the NPI-NH. The model includes assessment of BPSD symptoms, documenting current medical treatments, providing a checklist for possible causes of BPSD, offering evidence-based care plan suggestions to reduce BPSD, and an evaluation of the interventions applied. By regularly assessing symptoms and evaluating interventions aimed at alleviating these symptoms, the quality register facilitates value-based care [25]. However, supporting BPSD remains complex. Research has shown that an increased ability to accurately assess the needs of people with BPSD has been correlated with improved care and decreased levels of BPSD [26]. Yet healthcare professionals may lack the proper skills to perform sophisticated observations, or their assessments may be influenced by the emotional relationship they have with the person with dementia [27] or the level of distress caused by the BPSD [23, 28]. As a result, innovative tools are needed to provide objective personalised information that will help the healthcare professional to better understand an individual's needs.

## 1.2 The role of ICT solutions in dementia care

The role of ICT solutions in dementia care has been described in depth in the First Stakeholder Impact report (D2.7) so only a brief summary will be included here. ICT solutions have the potential to improve daily life for dependent and disabled people, including those with a diagnosis of dementia [29]. Various research projects over the past two decades have explored using sensor-based technologies for remote monitoring, environment monitoring and physiological sensing for people with dementia, including 'smart home' applications made possible by greatly improved wireless technology [30]. ICT solutions also offer the potential to improve the quality of BPSD care by providing additional assessment data based on the use of a multi sensor system. Improved BPSD care will in turn contribute to improved quality of life for the person with dementia and reduced costs for healthcare systems.

The advances fall into the following broad categories: 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. The most important requirements for sensor-based solutions are that they should be non-invasive and wearable [30]. Suitable sensors 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, and multimodal sensor shirts. The smart home technologies also show promise in collecting data and assisting in gauging slowly evolving events such as cognitive impairment [31]. It is reported however that most of the reviewed projects are experimental and have only been tested on healthy people.

As well as being non-invasive and wearable, the technologies must be practical, compelling, economic, and user-friendly if they are to gain widespread traction. If these conditions are met, study participants have consistently reported their willingness to trade privacy for technology solutions that enable them to remain independent. Families of people with dementia also profess themselves willing to pay for technologies that contribute to independence, safety, and quality of life.

The major sensing technologies currently being rolled out monitor the following activities:

1. Physical activity [32-35]
2. Sleep and night-time activity [36- 39]
3. Gait [40-42]
4. Daily living activity [43, 44]
5. Apathy [45, 46]
6. Eating [47]
7. Agitation/aggression [48]
8. Wandering [49, 50]

## 1.3 The goals of the Dem@Care system

The goal of the Dem@Care project was 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. The solution was 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 to answer the research questions specific to each setting. These were:

- For Dem@Lab:
  - 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?
  - Can the Dem@Care system assess the impact of behavioural disturbances, in particular apathy, and the completion of instrumental activities of daily living?
  - Can the Dem@Care system assess the impact of cognitive decline based on speech and vocal characteristics?

  - 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?
  - What is the acceptability among participants of using the Dem@Care system during a standard consultation in a memory centre?
  - What is the acceptability of introducing a follow-up monitoring system based on the use of ICT within participants' own homes?
- For Dem@Nursing:
  - What is the usefulness of the Dem@Care technology in this context?
  - What is the usability of the Dem@Care technology in this context?
  - 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?
  - Can support of people with BPSD be more effective with the support of the Dem@Care technology?
- For Dem@Home:
  - Is the system acceptable in the home; is it non-intrusive, and useful to the person with dementia and their family?
  - Are the functional requirements reflective of the reported needs of the person with dementia, as personally reported and reported by caregivers?
  - 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?
  - How autonomous and independent is the person with dementia, and can deployment of the system support this autonomy?

## 1.4 Evaluating the Impact of Dem@Care

It is evident that a growing body of research supports the benefits of ICT solutions for people with dementia, 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 the goals of the Dem@Care system, highlight what we have said the impact should be and how we can demonstrate that this impact has occurred (i.e. illustrate what the impact looks like). Appropriate outcomes were determined for each area of impact, with reliable and valid indictors and corresponding measurement approaches designed to demonstrate the extent to which Dem@Care achieved its intended outcomes. A short summary of the Dem@Care goals, beneficiaries and evaluation protocols are presented in this section and a matrix of evaluation measures has been included in Appendix A for ease of reference. The full evaluation methodology is available in the Initial Stakeholder Impact Report (D2.7).

### 1.4.1 Dem@Care Beneficiaries

There are four stakeholder groups that will directly benefit from the Dem@Care system, namely the person with dementia, the family of the person with dementia/informal caregivers, the health care specialist (e.g. general practitioner, geriatrician, psychiatrist, elderly care specialist, etc.) and the nursing and formal care personnel. Table 1 provides an overview of the extent to which each of these four groups may benefit from the identified Dem@Care 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)** | **Informal carer (relief and respite)** | **Healthcare Specialist (improved diagnosis)** | **Nursing/Formal carers (reduced staff needs)** |
|---|---|---|---|---|
| Dem@Home | P | P | S | |
| Dem@Nursing | P | S | S | P |
| Dem@Lab | | | P | |
| myLifeStory | P | P | | S |
| DemVoice | | | P | |
| HealthMon | P | P | S | |

### 1.4.2 Evaluation methodology

Outcomes represent the results of the Dem@Care programme. They encompass changes in knowledge, skills, attitudes, behaviour, motivation, decision-making, policies, and conditions, and they occur at an individual level (personal impacts) and at societal level. Not all outcomes can be achieved in the same time frame; instead chains of outcomes will build up over time. These chains typically involve:

1. Short-term learning
    - Acquisition of new knowledge
    - Results in changed attitudes, opinions and values, increased skills, changed motivations, and altered aspirations.
2. Intermediate (Medium-term) behavioural changes
    - 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
    - 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.

In this report, Dem@Care activities that support expected short and intermediate outcomes will be reviewed, and their likely contribution to longer-term outcomes will be identified. Some outcome indicators can be measured directly, for example physiological or cognitive improvements, but others may only be measured with reference to another activity or as behavioural responses in given situations. The Dem@Care evaluation has used direct measures where possible, although some impacts such as to subjective quality of life necessarily require more subjective measures (e.g. stakeholder testimony and opinions). Three distinct sets of outcomes will be discussed: personal, social, and scientific. Qualitative data was collected using semi-structured interviews and analysed using inductive content analysis. The interview protocol has been included in Appendix B. The overall evaluation approach will be consistent across the three areas, although the ease with which the target outcomes could be evaluated differs between the categories, as does the balance of quantitative and qualitative measures that will be used in each case.

All beneficiary groups were involved in the Dem@Care evaluation. As would be expected from a programme whose aim is to provide a technical solution to a group of end-users, this stakeholder group will have the greatest input to the evaluation. Academics, professionals, and policy makers are also important target audiences for dissemination, and their evaluations will be examined to determine scientific impact and to supplement those of the end-users when evaluating societal impact.

The results of the pilot studies from each environment and each site form the basis of the outcome assessment. Concepts evaluated during the @Lab pilots were measured by CHUN in Nice and by CERTH in Thessaloniki. Concepts evaluated as part of the @Nursing Home pilots were measured by LTU in Lulea and by CHUN in Nice, and those measured during the @Home pilots were measured by DCU in Dublin and by CERTH in Thessaloniki. Evidence will be summarised here, and full details of the pilot results are available in the three pilot evaluation reports. Most recent results are presented in the Final Evaluation Report (D8.5).

# 2 The personal impact of Dem@Care

The Dem@Care programme is expected to impact people with dementia, 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 is 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 [51].

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 [52]
- 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 people with dementia, independence and sense of improvement are most relevant for informal carers and sense of improvement alone for clinicians and formal care staff.

## 2.1 The personal impact for the person with dementia

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 person with dementia and thereby improve the QoL of their informal caregivers. In this regard, QoL consists of objectively measureable factors in combination with a subjective sense of what it means to have a 'good life' for the individual involved [53, 54]. A person's physical health, psychological state, personal beliefs, values, goals, expectations and concerns, social relationships, and their physical and cultural environment in turn influence this subjective measurement. In addition to supporting improvement in each of these areas, Dem@Care can increase perceptions of safety and provide access to services that would not otherwise be available as part of traditional dementia care.

### 2.1.1 Independence

The independence of the person with dementia was considered to have improved if the following outcomes were achieved:

1. The person with dementia was better able to take care of themselves

In the short term this meant that the person with dementia would become more educated about their condition, they would actively participate in their own treatment and care, and interventions would be more sustainable in the home environment. Achieving these outcomes would lead to reduced carer burden in the medium term, and reduced hospitalisation and time spent in residential care for the person with dementia in the longer term.

2. Facilitation of daily life

   This outcome involved increasing independence and autonomy in the short term, improving or maintaining the physiological, psychological, and social condition of the person with dementia in the medium term, and ultimately allowing them to remain living well at home for longer. It should be noted that dementia is a progressive condition and it may not be realistic to expect improvements in assessment metrics over longer periods of time; slowing the rate of decline is more likely.

3. Earlier diagnosis and more timely interventions that support stabilising the impact of dementia for the individual and potentially delaying the advancement of the condition.

**Autonomy and independence in daily life**

Each participant in the Thessaloniki @Home pilot lived alone. They used the Dem@Care system in combination with interventions chosen for them in response to complete neurological and neuropsychological examinations. Most participants in the Dublin @Home pilot lived with their spouses. They too used Dem@Care to support specific clinical needs identified during an initial needs assessment. Dem@Care also supported a personalised cognitive rehabilitation intervention for five of these participants. Post-intervention assessments found that participants improved their cognitive function, activities of daily living and emotional well-being, and sleep (see D8.5 Final Evaluation Report for a detailed presentation of these results). They became more aware of their personal capabilities and difficulties, and the Dem@Care system contributed significantly to these positive results as it: a) facilitated early detection of problems or issues that could not be identified through clinical assessment (e.g. interaction of physical activity and sleep patterns), b) provided objective measurements in each domain, c) enabled the development of successful personalized interventions based on the Dem@Care data such as those provided during the Cognitive Rehabilitation intervention in the Dublin @Home pilot, and d) provided guidelines and feedback directly to the person with dementia.

One of the most important ways in which Dem@Care supported the person with dementia's autonomy in every day living was via the messages (prompts, reminders, guidelines, and checklists) available to them through their system interface. Many of these messages were automatically generated from the analysis of integrated senor data and processed according to a specific set of clinical guidelines. In some cases, materials were developed to support specific cognitive rehabilitation goals such as using the phone and cooking a meal. The person with dementia and/or the carer is able to see the results of the data analysis across a day, week, and month and it helps them monitor their own progress and function is a variety of areas including sleep, physical activity, IADLs, and stress. This level of objective and timely feedback is not something that clinicians are typically in a position to provide in today's busy healthcare settings. Clinicians are, however, able to use the same messaging facility to communicate with people with dementia as they periodically monitor their progress, deliver interventions, and provide reminders of important daily tasks or upcoming appointments.

> *"I was about to hire a full-time person to take care of him, but I cannot describe with words exactly the feeling of being in my work in the morning and have full access all day from the tablet and see how he slept what he did if he is ok, if he took his medication etc. It is feeling of safety and relief that every caregiver of an elder person must have"* [@Home Carer Thessaloniki]

The most compelling evidence to support these achievements comes directly from participant statements. Many of the @Home participants felt that they had increased their autonomy and they felt more confident in their ability to take care of themselves.

> *"I feel kind of in control, do you know what I mean? In control of my day. Like, I wake up and I know exactly…".* [@Home PwD CSP5]

Two participants with MCI reported that they became more independent and active and improvements were seen in ADLs that has been identified as problematic in the initial assessment. Their family also noticed improvement; one family caregiver said

> "*I see that my father is getting better! He is more active and walking a lot*" [@Home Carer Thessaloniki]

Similarly in Dublin, one carer spoke of her husband's improved ability to manage charging his phone and taking it with him when we went out, and it is possible to see a reduction in her anxiety as she feels this has added to his general safety.

> *"He takes it up every morning and he puts it into the case and then he puts it into the charger at night-time. That's all you can ask for, to make sure that he has the phone on him."* [@Home Carer CSP1]

**Diagnosis**

The @Lab pilot successfully demonstrated that using Dem@Care as an additional assessment tool improved the early detection of dementia through its ability to detect fine subtle behavioural changes in the different patient groups. Several studies were presented in the Pilot Evaluation Reports (WP8) that illustrate that it is possible to differentiate between healthy, MCI and AD participants with relatively high accuracy rates based on sensor data alone. Moreover, people with AD can be easily detected by the system even in the early stages of dementia; something which is very difficult in other neuropsychological assessments. Results have also generally been found to correlate well with existing neuropsychological measures such as FUCAS, FRSSD, and MMSE.

### *Physical Activity*

The relationship between gait parameters and cognitive impairment was examined using ambulatory actigraphy during single and dual tasks. Results demonstrated that walking speed was slower in MCI and AD participants in both task conditions. In another study, we found that MCI participants had significantly reduced mean motor activity while carrying out directed and semi-directed activities, compared to healthy control participants [56]. Furthermore, no difference was found in motor activity between MCI participants with or without depression. These findings allow us to conclude that actigraphic measurement of motor activity during the evaluation of IADLs and motor tasks is a potential objective tool in differentiating between healthy controls and those with MCI or dementia. This novel approach is also capable of detecting early changes in MCI although results do suggest that depressive symptoms are not associated with motor activity in MCI subjects.

### *Speech Analysis*

The @Lab pilots also demonstrated the utility of automatic speech analysis as an assessment tool to improve differential diagnosis. Results from an initial study found that the automatic audio analysis could differentiate between healthy controls and MCI with 79 ± 5% classification accuracy; between healthy controls and AD with 87 ± 3% accuracy; and between MCI and AD with 80 ± 5% accuracy. A second study using mobile voice recordings found high accuracy rates for differential diagnosis based on the automatic determination of a cognitive vocal score. Fluency and free speech tasks obtained the highest classification accuracy rates between healthy controls and MCI (84 ± 4%), between healthy controls and AD (90 ± 3%), and between MCI and AD (83 ± 4%) [57]. These findings suggest that automatic speech analyses could be an additional objective assessment tool for identifying individuals with cognitive decline and for monitoring progression. The mobile nature of the assessment would also make it suitable for assessment in the home environment under the guidance of a clinician or perhaps with the assistance of a family member.

### *Video monitoring*

The use of a video monitoring system for automatic event recognition was explored as part of the assessment of IADLs in people with dementia. Participants carried out a standardized scenario consisting of several IADLs such as making a phone call while they were recorded by 2D video cameras [58]. The comparison between automated activity detection and direct clinical observation found high sensitivity and precision rates. Interestingly, no significant differences were found between the groups using an IADL scale which suggests that video monitoring as part of an ICT assessment tool might, in certain cases, be more sensitive and better able to detect fine changes in behavioural functioning than classic psychometric assessment tools.

The @Lab pilot also demonstrated the value of a fully automated quantitative assessment of autonomy levels in people with dementia based on merging extracted features from the participants' performance on IADL with the gait analysis described earlier [58, 59]. The combination of these two automatic assessments obtained even higher precision rates (83.67%) than examining IADLs alone providing further evidence that Dem@Care video analysis can provide a reliable and precise tool for assessing an individual's functioning in daily life, with results that clinicians can use for both diagnosis and treatment.

***Lifestyle sensing, Multi-sensor Fusion and Classification***

While in @Lab Nice, visual sensing is the lead component to extract a diagnosis, in Thessaloniki we introduced more sensors and components to explore their effectiveness and reinforce its accuracy. Lifestyle sensing in the form of manipulation of physical, daily objects, electrical appliances with embedded sensors were used to transform the @Lab in a smart space of interconnected objects for IADL sensing. This type of sensing is combined with the existing visual recognition techniques to shape the definitive recognized activities by semantic interpretation.

Statistical analysis performed over more than a hundred participants has revealed significant differences between the groups of different mental condition, in the way they perform many of the activities. It also revealed a strong correlation between specific activities and neuropsychological tests. Finally, a model was built, in the form of a highly accurate SVM model, using a multi-dimensional feature vector of 16 attributes (time duration and successful attempts of each activity) achieving 89.15±0.20% mean average accuracy.

### 2.1.2 Sense of Improvement

Increasing a person with dementia's QoL requires that they perceive improvement and a sense of autonomy in their physiological, psychological, cognitive, and social condition [53]. Given the subjective aspects of this measurement, the perception of the person with dementia is preferable to proxy ratings [54], although in later stages of dementia proxy ratings can be useful [55]. Findings from the @Home and @Nursing Home pilots found improvement in mood (as measured by the NPI, GDS, Hamilton, BDI, BAI), physical condition (measured as increased levels of moving intensity and active energy expenditure), sleep (as measured by the Dem@Care sleep sensors and the PSQI), IADLs (as measured by the Bristol ADL scale and clinical observation), social interaction (higher levels of social activity), and in almost in all areas of cognition (as measured by the MMSE, MoCA, and TEA). These improvements were mainly based on the participants' motivation to engage with new and advanced technology (sensors, tablets, user interfaces) and the personalized and effective interventions developed from a clearer understanding of the person with dementia's needs. The specific functionality of the Dem@Care system, ongoing monitoring and provision of objective data, and the person with dementia's ability to monitor their own status in a friendly and comprehensible environment, underpinned both of these factors. Participants commented to the clinician, “*It is like a game!*” [@Home Thessaloniki]

The evidence that supports improvement in each of the functional domains is summarised below. It is important to note that the participants in the @Home pilot in Thessaloniki had lower levels of cognitive impairment than those in the @Home pilot in Dublin; two had a diagnosis of MCI, one of mild dementia and one of more moderate dementia. In contrast, the participants in Dublin varied from mild to moderate and the main lead user progressed from mild to more advanced dementia over the course of his involvement with the Dem@Care pilots. In these instances, noticeable longer term improvements are difficult to see. Instead, stasis or a delay in advancement of the condition is the more realistic outcome.

**Physiological improvements**

The physiological functions that were most closely monitored during the Dem@Care pilots were sleep patterns and levels of physical activity. Many @Home participants experienced difficulty with their sleep and reported poor perceptions of overall sleep quality. Accurately reporting one’s own sleep patterns is difficult even when no cognitive impairments are present. Measuring sleep was highly beneficial for the person with dementia as daily feedback of objective sleep data challenged their perceptions and enabled them to build a more accurate picture of their real sleep patterns. Dem@Care also highlighted problematic areas and steps were taken to resolve these. For example, one case study found that the person with dementia’s perception of their sleep quality was driven in large part by hours just prior to rising for the day. This portion of their sleep was often disrupted as their wife got ready to go to work. The combination of realising that they got good sleep earlier in the night and a reduction in early morning disruption increased perceived levels of sleep quality for this individual in the short term.

> *“Well, I couldn’t imagine that I can wake up after 8 o’clock in the morning. I used to wake up before 5 o ‘clock!”* [@Home Thessaloniki]

Low levels of physical activity were found for some @Home participants. In these cases, the objective sensor data was used to educate the person with dementia about the value of maintaining adequate levels of physical activity and as a means to introduce interventions focused on increasing physical activity for these individuals. People with dementia found that ongoing monitoring of their activity levels provided them with the motivation to persist with the intervention and to remain active thereafter. These participants had also been educated about the positive impact that higher levels of physical activity could have on sleep quality and it was shown that as long as the participants were more active, there was an improvement in their sleep quality. As a result they were further motivated to maintain these higher levels of physical activity and use the Dem@Care system to monitor their progress.

**Psychological improvements**

The @Nursing Home pilots demonstrated that Dem@Care could provide meaningful information useful in the assessment of people with BPSD, above and beyond that provided solely by neuropsychological assessment. This more comprehensive understanding of patterns of behaviour improved the efficiency of care interventions for people with dementia. With the addition of Dem@Care sensor data in the assessment, the care interventions could be tailored to the individual's needs (e.g. directed towards peaks of distress and their associated triggers). As a result, interventions became more person-centred, timely, and preventative in nature, and ultimately more successful.

Participants in the @Home Thessaloniki pilots recorded lower GDS and higher QoL scores in their final evaluations than were found at baseline. These improvements were echoed in carer conversation in the final interviews.

> *"Basically, on the beginning I couldn't imagine that in a very short period my father's condition would become better."* [@Home Thessaloniki]

In Dublin, however, more variable patterns of results were found that were person-specific; they were closely related to their stage of dementia, to the specific areas of difficulty they were experiencing, and to the goals of their person-centred interventions. Very consistent self-reported results and proxy ratings were found across the study for the lead participant in Dublin. Given that a clear functional decline was seen across the same period for this individual, stasis could be considered a good outcome here. Quality of life self and proxy ratings increased over the course of the pilots for the second lead user. None of the intervention participants reported clinical levels of anxiety or depression at baseline, but all reported a positive impact following their intervention. One participant summed this up by saying:

> "*I have no fears at all about moving forward. I think that I am in… I hate the term "a better place" because it's an overused term, but it describes where I am at the moment. I think I am better in that sense. I think I have a better understanding of myself and what this means to me, and I think, hopefully, I'll be able to continue to handle it okay and better and just see where it takes us at this stage, because even if I didn't have it and I was talking about the future, we'd be sitting here saying, 'We don't know where it's going to take us*'" [@Home PwD CSP3]

**Cognitive improvements**

Increased MMSE scores were found for the participants of the @Home pilots in Thessaloniki, and improvements in cognitive abilities were found in the analysis of Dem@Care data over time. Carers also noticed improvement in patients' behaviour and cognition. These results reflect the fact that participants were more confident to be alone and felt better able to manage their daily routine. Specific cognitive improvements were seen following the cognitive interventions in the @Home pilots in Dublin. These included evidence of new learning (e.g. ability to learn how to use a new mobile phone) and evidence of retained cognitive abilities (e.g. maintaining the ability to cook a meal, use an iPad, and independently manage medication).

> *"Now he's coming back outside every so often and doing his, what do you call it, word search and that."* [@Home Carer CSP1]

**Social improvements**

Regular monitoring of daily activities in Dem@Care illustrated higher levels of social interaction among participants in Thessaloniki as evidence was found to support increased participation in activities outside the home. Increased social interaction was also found among dyads participating in the cognitive intervention in Dublin.

> *"We never spoke an awful lot. We are talking a lot more now. We are finding it easier to talk … as I explained, we would never have been ones for communicating very much and now we kind of are to a certain degree."* [@Home Carer]

One intervention in particular aimed to increase social interaction and participation in community activities for one woman with dementia. As part of this intervention, she engaged in weekly conversation about her life and interests with a therapist. These conversations were recorded and subsequently analysed in Dem@Care. She was also introduced to a choir group specifically for people with dementia and memory loss. Although this element of the intervention was not directly supported by the Dem@Care system, it was evident that enjoyed and valued her reengagement in social activities. Her communication skills across increased as a result of both aspects of the intervention.

### 2.1.3 Security and Safety

Although Dem@Care was not primarily conceived as a safety and security system, functional improvements and an increased sense of independence and autonomy give the person with dementia an increased confidence to manage their day-to-day lives. Dem@Care enables the individual to monitor their own health and well-being, and it shows carers and clinicians not only where the person with dementia needs support, but also where they are very capable of managing on their own. This reduces the likelihood of 'over-caring' and further enables the person with dementia to maintain their independence for as long as possible. Dem@Care reminders can support the person with dementia to remember important events throughout the day (e.g. taking medication), while system alerts can be used to highlight when important activities are forgotten. Dem@Care also provides a means to support new learning that can in turn increase safety (e.g. using and remembering to carry a mobile phone), while also providing a collection of sensors to manage safety in the home (e.g. motion sensors and smart sensors for plugs and doors), and it provides a means of supporting and evaluating personalised interventions designed to support the specific needs of an individual with dementia. Through-out, the person with dementia can be secure in the knowledge that the health and lifestyle patterns captured by the Dem@Care sensors are also available to their clinician, along with alerts and warnings of any potentially problematic changes that warrant closer examination.

Finally, based on interviews with individuals referred for diagnosis during the @Lab pilots, people were appreciative of the fact that additional new and innovative methods were being used to improve assessment and to detect early dementia-related markers. This was perceived as useful and increased feelings of security and safety as "*what [the clinician] might not see or hear, the sensors will detect*". People often stated that they felt well taken care of since we used modern technology to improve the work of the clinician.

> "*Wow…this is impressing all these technologies you use to measure and assess our performances…I feel like you are doing your best here to help the patients and to detect early if something is going not so well…I feel in good hands since you are working with the newest technologies*" [@Lab Nice]

### 2.1.4 Contribution towards long-term outcomes

A long-term goal of Dem@Care was to enable people with dementia to remain living at home for 10% longer. It has not been possible to provide direct support for this outcome and the original objective was perhaps too optimistic. However, the @Home pilots have been able to demonstrate that using Dem@Care has supported independent living at home and that it can increase the autonomy of the person with dementia even when they are being cared for by others in the home. Evidence of normal usage of electrical devices and confirmation that medications are being taken correctly, for example, provide objective evidence to manage the risk that family members may worry about if a relative with MCI or dementia is living at home alone. Ongoing monitoring and evaluation enables clinicians, family members, and the person with dementia themselves, to identify increasingly problematic patterns and support or scaffold these activities for as long as is practical and effective. Finally, maladaptive sleep patterns are cited as one of the most reported reasons for a person with dementia transitioning to long-term residential care. Dem@Care very successfully provides objective sleep information along with the ability to analyse sleep patterns over time, such that early changes in sleep patterns can be more easily identified and interventions put in place before sleep problems become ingrained and more difficult to resolve. Further longitudinal testing with a wider range of participants would be required in order to gather more real data about the potential impact of Dem@Care in the home environment.

## 2.2 The personal impact for the informal caregiver

Greater independence, improved quality of life, and a better economic position are important personal outcomes for informal caregivers and they form the second key objective of the Dem@Care system. Informal caregivers want to be able to support the person with dementia to the best of their ability while successfully managing their own physiological and psychological health and well-being. By directly supporting the needs of the person with dementia, Dem@Care can increase the independence of the informal caregiver and improve their quality of life.

### 2.2.1 Independence

The more autonomous the person with dementia can remain, the less direct support is needed from the informal caregiver and the easier it is for the carer to manage their own needs and facilitate their day-to-day lives. Carers appreciated the accurate and comprehensive knowledge that Dem@Care provided about the condition of the person with dementia and they were able to see first-hand improvements in participants' confidence to go about their day to day lives as a result of using the Dem@Care system and being involved in Dem@Care supported interventions. For one caregiver, this led to the ability to take a short break with another family member secure in the knowledge that the person with dementia could manage well at home with limited levels of support at key time periods.

> *"I told [Public Health Nurse] I was going away for the week in September and she said, 'Oh, how are you going to manage?' That's what all this [Cognitive Intervention] is about. I said, 'He's independent at the moment and we are trying to keep him as independent as long as we can.' And I said, 'I used to give him his tablets. Now he takes them himself'."* [@Home Carer CSP1]

Even for someone in the very early stages of dementia, caregivers are concerned to know if they are managing to take their medication correctly and to eat properly, how their sleep is and if they are getting enough exercise and stimulation. In Thessaloniki, family carers reported that they felt more comfortable going about their normal day, including going to work, as they were secure in the knowledge that they could remotely check in to see how the person they cared for was managing, and that any decline would be picked up the by the system and flagged to themselves and to the individual's clinician.

Most of the carers in the dyads that participated in the Dublin @Home pilots were spouses who lived with the person with dementia. They tended to be more involved in the use of the Dem@Care system and sensors and they found that this did take more of their time. They reported a number of difficulties using the sensors initially, and well-supported training periods were important to ensure acceptance of the Dem@Care system. If carers were unavailable for any reason, data collection did not tend to occur. In Thessaloniki, installations occurred at a later stage of the project and taking into account previous limitations, an overall setup of system and sensors with higher acceptability and less need for interaction was introduced. For example, the recruited participants lived alone and commercially available and not experimental sensors were used. Data were almost fully collected in all cases. Although in one instance the person with dementia was at a more advanced stage, this was not the case for everyone. The results suggest that people with dementia who live alone may be more motivated to use the Dem@Care system as they do not have a carer as close to hand. Those that do, seem happy to rely more on the carers for support that increases the interaction that these carers have with the Dem@Care system.

### 2.2.2 Sense of Improvement

In addition to having more independence and a greater sense of autonomy, carers reported improvement to their own psychological well-being. Psychometric results for the carer of the main lead user in Dublin show that anxiety levels after one year had declined from baseline levels. Unfortunately, this carer's anxiety started to increase again in recent months when her husband's condition began to deteriorate more rapidly. Given the degenerative nature of dementia, it is likely that there will be a time when Dem@Care is no longer able to support people with dementia and their carers to the same extent as it can for those at an earlier stage of the condition.

All carers spoke of the relief they felt when they began to see improvements in sleep patterns and cognitive function of those they cared for. For example, the children of one participant were very anxious about their father's condition, but following the clinician's interventions, they could see improvements in the patterns of activity captured by the Dem@Care sensors and they also reported to the clinician that their father was less likely to forget words that he would have been prior to the intervention. These carers reported using the Dem@Care system twice a day for 5 to 10 minutes each time. It was easy to use and they did not find a big imposition on their time. They felt that it was worth if in order to help them to identify issues that it would be impossible to know otherwise; for example, levels of physical activity during the day, amount of TV usage, and proper medication management.

It must be recognised that it is difficult to separate the impact of the use of Dem@Care system from the interventions that it is supporting. Although this is the case for personal impacts for both people with dementia and their informal caregivers, it becomes clear from the carer's narratives that the positive impact of participating in the project was at least in part related to the ability to spend more time with clinicians, therapists, and researchers than they would otherwise typically get to do under normal health care system management of dementia care.

> "*My experience has been brilliant because just being able to talk...You know yourself that if you can talk about something and get it out there it takes some of the pressure off you. That's what I... no, I found it fantastic."* [@Home Carer CSP 3]
>
> *"I have found that it has… those chats. And that's why one of the things that… And it was non-structured conversations we had at times which helped, and the very fact that you explained to me that I could, and [other researcher] said the same, that I could ring you at any time if I didn't really want to discuss something with [PwD] at the time, that would make him feel… difficult for him. So I found that that backup meant an awful lot. Even though I didn't have to use it that much. But the very fact that its there has been…"* [@Home Carer CSP1]

Finally, some additional safety features were discussed in the @Nursing Home pilots, such as installing sensors in the room of the person with dementia primarily in order to monitor sleep quality but also the risk of falling. Formal care staff and extended family members were particularly interested in the idea that events may be detected before the person has an accident in their room. Although this wasn't tested with any rigour in the @Nursing Home pilots in this project, it is clear that this functionality would be perceived as a great source of relief to carers and it is something that warrants further attention in any subsequent development of the Dem@Care system.

### 2.2.3 Contribution towards long-term outcomes

A long-term goal of Dem@Care was to enable the informal caregivers of people with dementia to have more time to themselves such that they can remain part of the active workforce and maintain their levels of social engagement. While it is not possible to provide a direct measure for this outcome (i.e. number of carers remaining in work with Dem@Care in comparison to those without), the successful attainment of the short-term personal impacts for people with dementia, the associated benefits to the informal carer in terms of the reduction in hands-on care required, and the perceived usefulness of Dem@Care as reported by informal carers, suggests that we are on the right path to achieving these outcomes. Longer validation studies with a larger number of participants and a greater range of caregivers will be required in order to provide clearer evidence in support of these goals.

## 2.3 The personal impact for clinicians and formal care staff

The Dem@Care system also aimed to deliver personal outcomes for clinicians and formal care staff. From a clinician's perspective Dem@Care should facilitate a timely and accurate diagnosis while delivering efficiencies in terms of time and cost. Diagnostic output should enable the clinician to develop individual treatment and care plans, improve patient follow-up, and provide a seamless transition to longer-term monitoring and assessment in a private home or residential setting. Formal care staff should feel a sense of improvement in their ability to deliver care through the accurate and comprehensive information that Dem@Care can provide about the person with dementia's condition. This data improves the ability to provide personalised care for an individual which, when successful, enriches the environment for all residents.

### 2.3.1 Timely Diagnosis

The inadequacy of existing methods combined with biased evaluations highlight the need for objective and systematic tools, and novel solutions for the assessment of dementia [60-62]. Several studies using ICT in the assessment of different domains show potential benefits of using ICT in clinical practice. Current research evidence and clinical expertise suggests that ICT cannot yet provide a direct diagnosis of Alzheimer's Disease and related disorders, but it can supply additional information for the assessment of specific domains (e.g. behaviour, cognition, and activities of daily living). This information can be combined with other clinical and physiological data to enable the clinician to make an earlier and more accurate diagnosis, and to provide more timely care, treatment and support.

### 2.3.2 The Dem@Care system uniquely exploits the medical knowledge of the clinician and the latest advances in ICT to enhance clinical workflow and improve dementia assessment processes. The @Lab pilot studies have found that multi-parametric remote monitoring and individualised analysis of physiological, behavioural and lifestyle sensor data are obtainable in a diagnostic setting. Furthermore, this novel ICT solution improves the early detection of dementia through its ability to uncover subtle behaviour changes in different patient groups; evidence of between-groups differences in physical activity, speech patterns, and activities of daily living have been described in Section 2.1 above. Dem@Care also facilitates the integration of ICT-based diagnostic processes into a complete remote care system that supports the on-going monitoring, treatment and care of people with dementia in their own homes and in long-term residential care settings.Improvement in treatment and care

Primary and secondary care clinicians, and a range of other healthcare professionals involved in the delivery of dementia care can benefit from the use of Dem@Care to support development and delivery of individualised treatment and care plans for people with dementia in a variety of settings. Dem@Care includes a monitoring and feedback loop for people with dementia and their informal caregivers that: a) monitors and assesses their health status by integrating data from a combination of wearable and ambient sensors, b) enables time evolving context-sensitive profiling to support reactive and proactive care, c) provides personalised supportive feedback. It also includes a clinical feedback loop that: a) provides objective observations regarding the health progression of the person with dementia and treatment effectiveness, b) alerts healthcare professionals about unfavourable trends, c) supports preventive care decision making and updating of care plans for the person with dementia.

The @Home pilot studies have also shown how Dem@Care can be used to monitor the on-going status of the person with dementia in their own homes, and also how the sensor data can be used to support interventions both in and outside the home. In this way, Dem@Care can benefit a range of healthcare professionals (e.g. formal care staff, psychologists, occupational therapists, and more).

> *"I think what is really good about it, is that it is very flexible so that you can see daily, you know what happened today… and then you can see over a week… and then you could go to over a month, what's the pattern?; then over six months, is there a general picture of decline in sleep performance?.. I think that that would be intensely useful to a clinician because as somebody who does assess people, and ask people on a daily basis in clinic 'How's your sleep?'… .nobody can tell me that"* [Clinician – @H Dublin]

> *"With the Dem@Care system, I was able to identify problems and issues that otherwise it would be impossible (for example the REM sleep issue with the second participants). Moreover, multilevel comparisons provide the entire base to*

> *design and implement specific and different interventions for each participant. And the most important, you can see and measure objectively the effectiveness of each intervention."* [Clinician – @H Thessaloniki]

In Sweden, based on the data from a limited study population, the @Nursing Home pilots have found that using Dem@Care when caring for people with BPSD results in significant improvements to the quality of that care. Previous research has shown that it is difficult to understand and interpret the complexity of BPSD and that care staff need to be supported in this regard. BPSD are common and challenging and there is obvious value to understanding the expressions and needs of people with BPSD in order to improve the assessment process and to better support their integrity and wellbeing. Nursing home staff work shifts and they can have difficulties getting a comprehensive picture of BPSD experienced by a particular resident, and an understanding of the care interventions best suited to that individual. It can also be difficult to build up a pattern that highlights the times during the day when symptoms are most problematic and the events that trigger these situations.

Incorporating Dem@Care into an improved assessment process enables healthcare professionals to combine their clinical knowledge with information from the Dem@Care sensors. These provide comprehensive and objective information on patterns of sleep, physical activity and stress for an individual over a period of time. This data helps identify problems and events that might be contributing to BPSD and facilitates more targeted and preventive interventions. Comparisons can also be made to earlier patterns of behaviours that in turn allow the effectiveness of different interventions to be evaluated, thereby providing improved quality of care in late-stage dementia, which benefits residents and carers and renders cost savings for the health care system.

The findings from the @Nursing Home pilots in Sweden also highlighted a change in the clinical reasoning of nursing home staff when incorporated Dem@Care data into their assessments; specifically the depth of discussions when assessing BPSD with the NPI-NH psychometric measure. Being able to see patterns of stress in the Dem@Care data made staff reflect more upon BPSD, identify possible causes, and target interventions in a more person-centred way. In essence, it increased the staffs' awareness of causes and preventative measures in a way that was not seen when the staff did not have access to Dem@Care information. Then discussions were more general and interventions pointed either towards handling BPSD when they arose, or towards 'making do' - interventions that the person might have liked, i.e. taking a walk when suitable.

The Dem@Care project originally only intended to run @Nursing Home pilots in Sweden. Given the success of deploying the @Lab and @Home protocols in new pilot sites, a short @Nursing Home feasibility trial took place in Nice, France just prior to the end of the final pilot. The potential to use Dem@Care as a means to identify the triggers for BPSD, and then to monitor the effectiveness of any interventions made, was one of two key areas of interest to formal care staff.

> *"Miss XY (the resident included in the trial) gets very agitated every day around the same time…then she starts shouting and knocks with a spoon against her table…when I hear her, I go into her room to calm her down…after I leave, a certain time later, she restarts shouting and making noises…can we find out with the help of Dem@Care what is the trigger of the reappearance of these symptoms after I intervened?"* [Doctor – @NH Nice]

The second was Dem@Care's ability to provide objective sleep quality measurements that could be fused with sensor data from other modalities; for example, nightly bathroom visits, late tv watching, physical activity and stress levels.  Staff felt that once they had objective information about the resident's sleep quality and other functional domains, they would be better able to design an intervention specifically suited to that individual and thereby be in a position to provide better quality care. The pilot study in Nice did not run for long enough to determine if these changes were sustainable over time, but the evidence from the pilot studies in Sweden suggests that this is possible. Although staff had a fair view on whether sleep quality was good or bad for a particular resident, the objective sleep patterns available in Dem@Care allowed them to confirm or correct these views and to build up a clear picture of sleep quality over time in a way that subtle changes in sleep behaviour could be recognised more easily. It also enabled staff to identify interactions between sleep, activity, and stress levels. In some cases the Dem@Care information also alleviated concerns; for example, even though a resident was awake a lot during the night, staff could see that they actually achieved a good total amount of sleep. This knowledge shifted the focus of a potential intervention from a situation where additional medications would be recommended to approve the sleep, to nursing interventions to lessen the number of awakenings during the night. There were also situations where daily moments of stress were pre-emptively addressed after observing their pattern.

### 2.3.3 Contributions towards long-term outcomes

The results of the @Lab pilots show that simply by employing the Dem@Care system in clinical practice, the clinician's workflow can be facilitated and the quality of their work improved. The ability of Dem@Care to support differential diagnosis quickly (in about 20 minutes) and accurately will be of significant interest to clinicians working in memory clinics and other diagnostic settings as they demonstrate the additional value of ICT use in clinical practice for routine assessments without an accompanying increase in workload. Some staff education is required but the level of technical knowledge needed to use the system is low, and this effort is minor in comparison to its added value. More generally, behavioural, cognitive and functional status can be monitored objectively without the presence of the typical observer's biases. These results will improve diagnostic accuracy and also clinical decision support and the selection of appropriate interventions. Prognosis will also improve on the basis of increased knowledge about early indicators of developing progression towards dementia pathology. As a result, they can better inform patients and their families about risks and the specific actions need to be taken.

It should also be noted that the management of BPSD in Sweden takes place within the context of an established work process, the BPSD registry (**www.bpsd.se**). The use of a structured quality registry such as this facilitates the possibility of using Dem@Care within this work process to strengthen value-based person-centred care, as clear measurements and continuity in follow-up indicators of quality of care are strategies can be incorporated into a computerised registry such as this. Separate funding has been secured to progress the @Nursing Home studies in Sweden with a view to providing further evidence to support this recommendation.

# 3 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 the social impact of Dem@Care is quite difficult as they occur on a much wider scale than those personally relevant to people with dementia, informal and formal caregivers; for example, at strategic or national levels. The distinction between economic, financial, environmental, and social impacts is also difficult to separate in reality [63]. Furthermore, while some of the expected outcomes are visible in the short-term; many others will only become apparent in the longer-term. The macro-level evaluation of Dem@Care therefore presents a greater challenge than the previous micro-level assessment. That said, many of the societal outcomes build upon the personal outcomes successfully attained for our stakeholders, in combination with those impacts evident at a meso-level (community, organisation, networks, and industry sectors).

## 3.1 Economic impact

Wide deployment of ICT solutions is 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 [64]. Economic modelling would be required in order to quantify the costs generated by organisational change associated with the use of Dem@Care in diagnostic and formal care settings. A specific analysis of potential cost savings was not part of the scope of the Dem@Care pilots, although a series of potential economic impacts were identified. These were:

- The potential to improve early diagnosis through more widespread screening practice using the Dem@Lab system.
- 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 person with dementia 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.

Evidence for the cost effective nature of Dem@Care in the lab environment is based on our ability to demonstrate its role in improving early diagnosis. The findings presented in Section 2 demonstrated that dementia-related signs in voice and gait could be detected earlier with the help of Dem@Care than when using traditional assessment tools alone; the latter lack the sensitivity to detect these early changes. Dem@Care can also provide additional voice-specific information that cannot be gathered easily through observation in a clinical setting; for example, utterance duration, filler typology, and analysis of voiced and voiceless segments. Furthermore, by using Dem@Care in clinical practice clinicians experienced a time saving that can potentially be used to see a larger number of patient referrals.

In formal care settings, potential economic benefits arise from improved workflow, clinical reasoning and intervention selection. While there is an obvious value to understanding the expressions and needs of persons with BPSD, and thereby being able to better support their integrity and wellbeing, potentially improved quality of care in late-stage dementia can also result in cost savings for the health care system. For example, the total cost of dementia care in Sweden in 2012 was 60.5 million euro, with a cost of care for each person of 40,000 euro. Unfortunately healthcare systems have very poor dementia-specific data so it is not possible to separate out the cost of care of people with BPSD. That said, it is easy to see how even a 10% improvement in care (e.g. shorter periods of BPSD) would have a considerable economic impact.

Dem@Care specifically addresses the assessment and management of BPSD by providing new and more objective information to nursing home staff that improves BPSD understanding and enables the implementation of personalised BPSD interventions. This added clinical value is achieved with relatively low impact to the care staff. Furthermore, the use of Dem@Care can easily be incorporated into established work structures, including the use of the BPSD registry in Sweden, with minor methodological adaptations. The experience in the @Nursing Home pilots suggests that the implementation and wider use of Dem@Care in residential care environments is possible in the near-term and is likely to result in economic improvements in the medium to longer term.

It is more difficult to quantify the potential economic impact of Dem@Care in the home environment. It can facilitate efficient care provision for the person with dementia in that they can (1) monitor their health and functional status over time, (2) receive more regular guidance and support from their clinician than is available when relying on face-to-face contact, and (3) use the Dem@Care functionality (e.g. calendar, checklist, reminders) to support day-to-day activities that otherwise might need to be supported by a family caregiver or home help. This leads to increased feelings of autonomy that are underpinned with the knowledge that the clinician is fully aware of their status and will be alert to pattern changes that may signify the need for modified care plans or increased levels of support. As was seen in the @Home pilots in Thessaloniki, the Dem@Care functionality may support a person with dementia who lives alone to remain doing so for longer.

Informal caregivers can also monitor health and lifestyle information pertaining to the person they care for, with their consent. Checklists and reminders that guide the person with dementia through the day can also alleviate some of the need for the caregiver to be always present. This in turn means that the caregiver could potentially remain working for longer, or they may be able to delay the need to reduce their working hours to care for the person with dementia. It can also enable caregivers to maintain social hobbies and interests outside the home, which is protective of their own mental health. Finally, Dem@Care allows clinicians to monitor and provide guidance to multiple patients in a time-efficient manner, and to more easily deliver interventions in the home environment, provide supported practise between intervention sessions, and to more easily evaluate the success of these intervention. Each of these aspects enhances the quality of care for the person with dementia that should itself lead to economic benefits for national health and social care systems.

## 3.2 Social impact

The wider social impacts of the Dem@Care system focus on the inclusion of the person with dementia in the community and increasing the awareness and understanding of dementia in the general public. For example, enabling the person with dementia to remain an active citizen for longer thus avoiding isolation in their own home or nursing home. Successfully realising outcomes at a societal level builds on the successful attainment of the personal outcomes for each of the stakeholder groups.

In the nursing home environment, Dem@Care facilitated an improved understanding of BPSD and the ability to develop personalised interventions to reduce the distress caused by these symptoms. This both increases the quality of life of the person with dementia and reduces the social disturbance cause by the BPSD this enabling the individual to spent more time in the company of other residents. Furthermore, improving the understanding of BPSD and reducing the general impact of the distress it causes, reduces the stigma associated with these symptoms by recognising that people with dementia have various and highly individual degrees of difficulties; some which that they share with people who do not have a dementia diagnosis.

A number of case studies in the home environments illustrate how Dem@Care supports people with dementia to remain part of their wider social environment. The ways in which it did so varied across individual participants. In some cases Dem@Care provided a means to manage and remember appointments and activities outside the home, and to support external interventions by reminding the person with dementia of dance classes, exercise classes and group sessions, and motivating them to attend. For others, Dem@Care supported new learning and scaffolded existing activities to enable, for example, learning how to use a new phone so that individual could leave the house alone and both he and his wife were secure in the knowledge that he could make a phone call if he needed to. Increasing the person with dementia’s independence enables them to participate more in community activities, but it also increases the independence of their family caregivers by giving them time to maintain their own levels of social contact whether that is in a work or community environment. In one case study, the spouse of a person with dementia felt comfortable to go on a short holiday with her sister. Although some extended family support was needed, an objective knowledge of her husband’s level of function (e.g. that he can cook for himself and use his new phone) enabled that support to be minimised and directed to the times of the day when most needed.

Case studies have also shown that even when the use of Dem@Care is small the impact can be significant. For one participant in Dublin where Dem@Care supported the delivery of a personalised cognitive intervention, it demonstrated the improvement in her language skills and in her ability to hold a conversation following recorded weekly sessions with the therapist. However, the primary goal of this Dem@Care intervention was to increase her opportunity for social engagement. Her love of singing became apparent and she had been a member of a choir for many years but had left when she began to have difficulties keeping up with the other choir members. She was introduced to a choir group specifically for people with dementia and memory loss and the improvements in her mood, activity and conversation levels, and quality of life further increased. Recently, she and her husband have been interviewed for a national newspaper in Ireland. They describe her life, learning to live with the difficulties caused by her dementia, and how participation in the choir and maintaining her social interaction with others have been so important to them both. This newspaper has national reach and it describes a very real account of living with dementia. It is not sensationalised nor watered down, and it contributes to educating the general public about the realities of living with dementia. But, it is important to note that blending technology and the use of face-to-face contact, and the existence of an intervention suited to her needs (e.g. the choir) were integral to the success of the intervention. Dem@Care, therefore, supports the delivery of dementia care but it does not replace the human aspect of that care.

It is also important to consider proxy indicators of social impact, such as the social response to the project's 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.

A Dem@Care symposium was held on July 20th at the Alzheimer's Association International Conference 2015 in Washington DC and chaired by Professor Philippe Robert. Attendees had clinical, academic, industry, and technical backgrounds and it was a significant opportunity to present the personal and scientific impacts of the Dem@Care project. Dem@Care was also presented at the 25th Annual Conference of Alzheimer Europe 2015 in Ljubljana. Here, we reached a broad audience as this conference uniquely brings together people with dementia and their carers, policy makers and civil servants, health and care professionals, academics and researchers, staff and volunteers of Alzheimer associations and other dementia-related voluntary and advocacy groups, and representatives of the pharmaceutical and technical industries.

In addition to the recent newspaper article mentioned above, Dem@Care has presented to the general public in a variety of ways; for example, during health and technology fairs, to national committees and local administrators (municipalities), to organisations whose partners are working on the project, at university research expos and at various dementia Information events. Dem@Care has also been presented on a very popular morning programme on French television. But, there is a long pathway between applied research and the full 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 was possible with this project, and some time after research results have been disseminated. It is important to now build on the successes of Dem@Care and to continue to look for ways to ensure the continued social engagement of people with dementia and their carers, and increased levels of knowledge and understanding of dementia among political, policy-making, healthcare, and scientific communities and in the general public.

# 4 The scientific impact of Dem@Care

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

## 4.1 Advancing the technical state-of-the-art

Dem@Care provides improved remote management and care solutions for clinicians, care staff, informal caregivers, and people with dementia, with dynamically evolving accurate and meaningful feedback. This is achieved by effectively coupling state-of-the-art data- and knowledge-driven analytics with powerful graphical user interfaces that help end users to easily access, search and visualise the Dem@Care knowledge base. The system's modularity allows dynamic adaptation of sensor deployments per-site and per-individual, according to criteria such clinical need, areas of interest, comfort, and logistics. In addition, intelligent event-driven mechanisms enable context-sensitive and personalised supportive feedback via flexible, adaptive visualisations of daily activities and personalised alerts.

From a technical perspective, Dem@Care expanded the current state-of-the-art multi-sensing and lifelogging technologies and knowledge modelling strategies. Multiple sensors (physiological, life-style monitoring, and audio) were deployed to obtain a richer description of the daily life, activities, and behavioural patterns of people with dementia. Details descriptions of these achievements are available in the deliverables from each of the technical work packages and they have been summarised below:

### 4.1.1 Visual sensing

- Addressed several challenging problems in visual sensing, from methods to easily deploy our visual components using in colour-depth sensing, to control approaches to automatically and dynamically tune our multiple people tracking algorithm in colour and/or depth image sequences (WP4, WP5).
    - Developed a hybrid framework for multimedia knowledge representation, semantic temporal alignment of multiple concept streams (WP4 components), the combination of these modalities for complex event recognition, and the management of the uncertainty that these sources of information carry.
    - Developed a spatio-temporal, real-time system for accurate activity recognition (WP4, WP5) using colour-depth sensing and based on semantics about the scene, the person body state, and domain knowledge about activities of daily living (WP5).
    - Improved activity recognition methods have reached a speed of up to twenty times that of the previous state-of-the-art methods.

- Developed new approaches for the perceptual analysis of egocentric video content that allow for more efficient recognition of objects, activities, and events thus reducing the uncertainty of SOA computer vision tools when applied to this content. This includes the fusion of electromechanical sensor outputs and video data for increased efficiency of activity recognition. The impact of these advances is particularly suited to the analysis of life-log data with applications beyond the dementia field. These include broad use with the general public around the idea of healthier lifestyles and more specific fields such as health care and sports performance (WP4, WP5)

### 4.1.2 Physiological sensing

- Extension of the existing capabilities of the physical activity (DTI-2) sensor with regard to the measurement of stress levels. Agreement was found between increased levels of measured stress and observational analysis by nursing home staff (WP3).
- A study was carried out for exercise detection via fusion of physical activity (DTI-2 sensor) measurement and lifestyle monitoring (SmartThings sensor) data. Analysis of ground truth data and comparison to observational findings provides a number of objective performance measures such as precision and recall of each exercise, which were, for example, 100% and 90% respectively for lifting weights, and 75% and 75% respectively for climbing stairs (WP3).

### 4.1.3 Knowledge structures

- Developed a unified framework for knowledge-driven event recognition with uncertainty representation to combine and interpret multi-sensor outputs in a meaningful and robust manner (WP4).
- Developed an unsupervised framework to mine and learn primitive to complex events in order to continuously enrich and update our knowledge-driven approach for complex activity recognition. This in turn ensures the continuous monitoring of people in unconstrained scenarios (WP4, WP5).
- New vocabularies and ontologies have been developed for capturing clinical and personalised knowledge. To promote reusability, extensibility, and interoperability, these models extend existing upper-level ontologies, such as DUL and LODE, capitalising on and specialising in existing ontology patterns. All ontologies have been published in public repositories (WP5).

### 4.1.4 Reasoning methods, rules, associations and algorithms

- Enriched state-of-the-art sensor fusion technologies with spatio-temporal reasoning in order to deal with noisy and incomplete data from real-world environments; for example the fusion of actigraphy data from the DTI-2 sensor with SmartThings (WP3).

- Development of a new framework for rules processing to improve activity and abnormal behaviour recognition with Semantic Complex Event Processing and the use of ontologies (WP3, WP5).
- Novel knowledge-driven analytics and reasoning are used to fuse and derive high-level behaviour interpretations, while data-driven analytics continuously update the underlying models to cope with behaviour variability and to support various personalisation services (WP5).
- Developed innovative analysis (periodicity detection) of longitudinal personal data this providing valuable clinical insights into the routines and habits of the person with dementia, which can be used to identify periods of disruption and points of lifestyle change (WP4).
- Employed unified context and uncertainty representation and scalable hybrid reasoning to interpret the multi-sensor outputs in a meaningful and robust manner (WP4, WP5).
- Carried out data mining of multi-sensor data to produce higher level interpretations of activities and events that have already been extracted by the corresponding processing algorithms (WP5).
- Developed a new, highly accurate method for the objective assessment of dementia (control / MCI / early-stage Alzheimer's Disease) and autonomy based on data from event recognition using visual sensing, lifestyle sensing and machine learning methods (WP4, WP5, WP7).

### 4.1.5 Visualisation and interfaces

- New graphical user interfaces were developed to visualise dynamically evolving personalised feedback, with access to problems and events, and activities and measurements, thus enabling scheduled problem checks, alerts, and other automated interventions (WP6).
    - For the person with dementia, it is a complete adaptable interface for monitoring and enablement that obeys priorities of detected and desired real-time activities.
    - For the informal caregiver, it provides information about the well-being of the person with dementia that can be accessed remotely.
    - For the clinician, it is a comprehensive toolbox for discovering detailed causes of problems, including but not limited to BPSD, and for obtaining a better understanding of patterns of change over time.

- Extensive sets of activities and problems stored in the Dem@Care knowledge base are displayed such that low level sensor data could be flexibly visualised and shown at variable aggregation levels.
- Demonstrated how remote management and care can rely on scheduled problem checks, alerts, and extensible questionnaires for obtaining self-report measures of sleep quality, physical activity, and mood. The value of manual reminders has also been confirmed (WP6).
- Illustrated how picture diaries (lifelogging) can support reminiscence and help create dialogues about daily activities that occurred in the past few days (WP4, WP6).

### 4.1.6 Integration and Orchestration of Sensing, Analysis and Clinical Applications

- Advanced state-of-the-art in AAL with an integrated, holistic framework targeted to dementia care. Most state-of-the-art approaches either employ a small number of sensors for monitoring or offer knowledge-based services such as context-modelling and interpretation, while their combination remains limited. In contrast, Dem@Care has successfully combined both approaches with rich multimedia analysis and tailored, intelligent interfaces (WP3, WP4, WP5, WP6, and WP7).
- Established a secure prototype for real-world usage in the sensitive clinical context of Dem@Care. Through the use of combined state-of-the-art protocols, such as OAuth and REST, the system provides secure transactions, storage and user authentication. Furthermore, privacy is ensured as users of different roles and privileges can authorize data access, e.g. from an end-user to his carers and doctors (WP7).
- The infrastructure built is extensible, modular and interoperable, rendering it future-proof and versatile to support many scenarios. On the sensor layer, Dem@Care has integrated many heterogeneous sensor APIs, both open (even from within the consortium) and proprietary ones, covering modalities with more than one sensor and profiting from the affordability and comfort of the latest sensor technology in retail. Sensor modules and analysis components (multimedia and semantics) are both integrated in a modules, well-defined manner using web standards (such as WSDL) and semantic interoperability, supporting dynamicity of new data providers at any point (WP3, WP4, WP5, WP7).
- The implemented orchestration capabilities allow the system to adapt to and facilitate diverse usage scenarios. The modular, universally described components are invoked by the backend infrastructure in accordance with each scenario. For instance @Lab implements a guided process of three-phase lab trials, automatically activating and de-activating sensors and prompting the user, while @NH and @Home feature file uploads, online data retrieval daily and in real-time. These functions are complemented by the front-end implementation, either by guiding and configuring sensor data retrieval and analysis or visualizing results (WP6, WP7).

- Based on the above, system integration allows for deployments adapted to both a usage scenario and an individual, optimally addressing personalized care. Indeed, especially the @Home Thessaloniki pilots have exploited this ability by targeting specific areas of interest (e.g. sleep in relation to TV watching or walks) by customizing and iteratively adjusting deployments at each visit. This integration feature of the system is enabled by the coverage of each modality by different sensors, the ability to add or remove any number of supported sensors (at run-time) and the universal format of sensor data to be analysed and displayed regardless of provider (WP5, WP7).

This innovative and tailored approach enables valuable clinical insights into the diagnosis and care of MCI and dementia. It provides clinicians with the ability to highlight deviations from healthy individuals @Lab and from longitudinal patterns @Home and @Nursing Home; for example, periods of disruption and points of lifestyle change could be identified and appropriate interventions made. Long-term data collection also facilitated the development of new data mining techniques and a number of datasets are available for industry benchmarking.

During the lifetime of the project, sensor synchronisation issues frequently came up, particularly in the home environment, due to the use of sensors with offline data collection, and the need for the synchronisation process to be managed by people with dementia and their caregivers. While later on, some pilots replaced initial sensors, other end-users and clinicians were already too accustomed to their use. In future efforts, pilots should ensure to use unobtrusive sensors, with synchronisation processes that are as automated as possible and that do not require any technical knowledge on the part of the person with dementia or the carer, especially now, that such technology can be found in retail. In this direction, and in a commercialization effort, Dem@Care has piloted such sensors in the context of a mobile health application setting and built more compact, deployable and affordable renditions of the system (D9.12).

## 4.2 Advancing the clinical state-of-the-art

The Dem@Care system provides a novel and holistic solution that supports all aspects of the clinical management of dementia including diagnosis, preventative care decision-making, and the timely updating of care-plans for the person with dementia. By integrating information from multiple wearable and ambient sensors, and employing context-sensitive profiling over time, it provides clinicians with objective observations regarding the health progression of the person with dementia, alerts them to the presence of unfavourable trends, and enables the creation of personalised and preventative interventions. A feedback loop for people with dementia and informal caregivers facilitates their ongoing monitoring of the health status of the person with dementia and it enables them both to receive personalised supportive feedback automatically from the Dem@Care system and via messaging from the clinician. The detailed clinical impacts for each of the Dem@Care end user groups have been presented in Section 2 above. The ways in which Dem@Care advances state-of-the-art clinical management and care of dementia is summarised below:

### 4.2.1 Assessment and diagnosis

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. Standard diagnostic scales also fail to fully capture the complexity of dementia. The @Lab pilot successfully demonstrated that using Dem@Care as an additional assessment tool improved the early detection of dementia through its ability to detect fine subtle behavioural changes in the different patient groups. Dem@Care successfully differentiated between healthy, MCI and AD participants with relatively high accuracy rates based on sensor data alone.

The test and evaluation of the Dem@Care system in the @Lab environment represents a first step in a new innovative approach for supporting and improving the diagnostic process for people with dementia. It should be noted that the @Lab protocol was never aiming to 'replace' traditional diagnosis tools for dementia such as MRI imaging or PET scans which are always required in addition to neuropsychological tests, but rather provide the clinician with additional relevant information about a patient's cognitive and functional status and perhaps highlighting signs of risk before the classical markers appear. Furthermore, it is possible that people find the experience of undergoing Dem@Care testing stressful; a problem that occurs with psychometric tests such as the MMSE, for example. For this reason, it is important to continue to collect longitudinal data and repeat the tests and the @Lab protocol to reduce this risk of contamination of the performance assessment due to high stress levels. At the pilot site in the hospital clinic in Nice, CHUN, in collaboration with CERTH, intend to repeat the Dem@Care @Lab recordings with their patients over a longer period of time in order to obtain as accurate data as possible. However, it will always remain a factor to take into consideration and it is important that the clinician has enough expertise to carry out the assessment and take time to explain to the patients what tasks will be required and why, so that the person feels as comfortable as possible and stress levels are minimised.

The added value of the Dem@Care @Lab assessment is, after all, that the data obtained by the sensors is captured objectively and not by a human observer, which is likely to make these data more reliable and accurate. The aim with the Dem@Care @Lab protocol is to detect fine subtle changes in behaviour, such as abnormalities in gait, speech production or execution time for ADL tasks; markers which are often not detectable by a clinician's eye and thus not captured by the traditional tools. Additionally, these markers may be more ecologically valid since they form part of a person's natural behaviour where certain neuropsychological tests are criticised for being artificial and not suitable for assessing performance in 'real life' settings.

The exploitation of the findings of the evaluation into regular clinical practice will be dependent on additional research efforts. In order to demonstrate clinical usefulness and to receive recognition in the clinical scientific and medical community, further tests and validation of the technologies is required with larger cohorts. Similar results from these studies could increase the likelihood that Dem@Care will become a routine part of clinical procedures when diagnosing dementia. Some technological improvements will be required to support these additional studies. Firstly, information from different sensors must be quickly and reliably integrated in real-time with meaningful automated interpretation of detected behaviours. Secondly, the visualisation of the recorded data must be immediate, accurate, and easily understandable to allow for a more complete assessment of a patient's cognitive and functional status.

### 4.2.2 Clinical trials

In recent decades, many promising disease-modifying treatments for Alzheimer's disease have been proposed. However, clinical trials conducted on treatment efficacy have not lead to any important breakthroughs. There is a growing consensus that this can, at least partially, be explained by methodological difficulties, including the inclusion of participants that are already in the later stages of the disease progression, and the selection of outcome measures, such as dementia conversion rate, which are not sensitive enough. Most of the current assessment tools have been accused of being artificial, lacking in ecological validity, and easily confounded by factors such as the person's emotional state. These trials typically target recruitment of people at the very early stages of dementia when memory functions are still preserved. Dem@Care could have a direct and beneficial effect on the selection of people for enrolment in clinical trials by allowing researchers to define new and possibly more accurate outcome measurements, and to conduct testing in more ecologically valid environments.

### 4.2.3 Treatment and Care

Managing BPSD is one of the major challenges in the care of people with severe dementia and it consumes considerable healthcare system resources. The assessment of specific circumstances surrounding BPSD and their contribution to the expression of BPSD for a particular individual is complex and dependent on many factors such as the skills and knowledge of staff and their access to accurate and reliable clinical information. Dem@Care advances the management of BPSD by improving the assessment process. It provides reliable and specific clinical information regarding patterns of sleep and patterns of stress/anxiety. This information has been shown to contribute to the development of more specific care interventions that are adjusted to the needs of each individual, and there is much evidence that personalised care interventions can significantly improve the situation of the person experiencing BPSD.

Clinicians are also interested in understanding everyday functioning of individuals to gain insights into difficulties that affect quality of life, and to assist individuals in completing daily activities and maintaining independence. Everyday functioning encompasses a range of daily functional abilities that individuals must complete to live competently and independently such as cooking, managing financial issues, and driving. In addition, deficits and changes in everyday functioning are considered precursors to more serious cognitive problems. Dem@Care is an ecosystem of connected devices, systems and services that provides a comprehensive view of the person with dementia's lifestyle, behavioural patterns and daily activities, identifies potentially problematic areas using individualised problem-detection parameters, and examines these patterns to identify improvement, stasis, and deterioration over time. Dem@Care also provides people with dementia and their families with relevant information about their health, including health education and lifestyle management material. They in turn become more knowledgeable and aware of their health condition, and better equipped to safely assume responsibility for their own self-care. This significantly advances the typical clinical workflow for dementia care management.

Evaluation of the Dem@Care system in nursing homes and in private homes indicates that it can provide additional clinical value in the provision of dementia care. Results have been beneficial to each of the end-user groups and the system has generally been regarded as acceptable for use in these settings. As would be expected different combinations of sensors are most useful depending on the care setting and the clinical needs of the person with dementia, which validates the Dem@Care Toolbox approach to sensor deployment. However, the pilot studies involved a limited number of participants in each setting. It is, therefore, difficult to generalize these results to other nursing homes. The expansion of the @Home pilots from Ireland to Greece supports the mobility of @Home protocols to other European countries, albeit on a small scale.

Many factors can influence the use of a multi-sensor system in these clinical contexts. Important issues for future exploitation will be technical performance, robustness, and ease of use of the system. Although general levels of acceptance were good, a number of usability issues were identified that will require technical development before this can be achieved. Improvements are also needed with regard to sensor integration, fusion of data from different sensors, and presentation of key clinical indicators in clear, accurate, and easily understandable reports. Ease of use will be especially important to the deployment of Dem@Care in clinical practice as the use of multi-sensor technologies is not as yet fully accepted, nor is it common practice. It is anticipated that more and larger evaluation studies are needed to show the ease of use and effectiveness of the system in order to convince clinicians in caregiving settings to invest in a technical system such as Dem@Care.

Finally, a significantly more compact by-product of Dem@Care, HealthMon, has been created to facilitate its exploitation as a commercial product. HealthMon is a mobile health-monitoring platform capitalizing on instant feedback. End-users are equipped with wearable sensors (currently Microsoft Band), directly linked to the HealthMon mobile application. Sensor metrics, such as steps, heart rate and posture, are fused together and interpreted according to user profiles, with the potential to produce alerts (e.g. high or low heart rate, posture chance signifying a fall). Real-time detection and alerts are streamed over the Web, immediately notifying the end-user as well as previously nominated individuals such as family, friends or a medical doctor.

## 4.3 Advancing the ethical state-of-the-art

Ethical issues remain a cause of concern when using technology in healthcare settings and with vulnerable populations. Ethical dilemmas arise on a daily basis for those providing care for people with dementia. The way in which these dilemmas are approached has significant impact on the lives of people with dementia and their caregivers. Good, ethical care recognises the value of the person with dementia and it aims to promote their well-being and autonomy. 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, and the way in which people with dementia feel that they are valued individuals, is often far more important than the particular structure or format of services (see D2.1, Ethical Literature Review and D2.5, Ethical Guidelines for a comprehensive discussion of ethical requirements). Dem@Care sought to advance the ethical debate by providing insight into a number of key questions:

- 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 person with dementia 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 their informal carers?

### 4.3.1 Informed consent

The high-tech nature of AAL may make it difficult for the person with dementia to fully understand what they are consenting to. A high level of vigilance is required from researchers and clinicians to explain the function of the Dem@Care system as simply and as clearly as possible and to demonstrate the operation of each of the sensors to make it easier for the participants to see what is involved. A rolling consent process should also be followed whereby, at the beginning of each visit, the researcher or clinician should outline the aims of the Dem@Care project, the nature of the data collection or intervention that is taking place, and reconfirm that the person with dementia and their carer are happy to continue to take part. In some cases the person with dementia was unable to fully understand the wider aims and objectives of the Dem@Care project. In these situations, a "task-specific" informed consent approach was followed where the person with dementia's capacity to understand what was being asked of them in the moment was evaluated and if sufficient understanding was evident, consent was established in relation to that particular task. This process was repeated for each new task.

The cognitive and functional capabilities of people with dementia decline over time and some found it increasingly difficult to manage the Dem@Care sensors and they became an additional source of stress for the person with dementia and for their caregiver. This highlights the need for ongoing evaluation of sensor suitability as the needs and preferences of the person with dementia changes. Therapists involved in the cognitive intervention in the Dublin @Home pilots also expressed the view that particular caution and consideration of potential ethical challenges is required when working with a person with dementia who is experiencing significant cognitive impairments.

In situations where the person with dementia is unable to provide informed consent, proxy consent is obtained, usually from the primary caregiver. It can be difficult in these situations to ensure that consent reflects what the person with dementia would have wanted if he or she were able to provide informed consent themselves. Alongside proxy consent, the person with dementia’s reactions to the sensors and interventions is a useful guide to their feelings and together these can be used to determine ‘rolling’ consent throughout the participation period. For example, if the person with dementia in the nursing home didn’t want to put the DTI-2 bracelet on, the staff just waited and tried, often with success, at a later point. In the home environment, heightened levels of stress and increasingly negative reactions at the point where sensors were to be used were interpreted as indications that the person with dementia was no longer giving their consent to participate. They were offered the option to completely withdraw from the study or to continue to participate in an expert capacity but without the need to use the sensors on a daily basis themselves. The latter option was most often selected as it enabled the person with dementia to remain involved with the research and in regular meetings with the clinician. This raised the additional challenge of the need to manage exit strategies from these types of research and pilot projects sensitivity and in a slowly decreasing manner rather than at a single point in time.

Finally, the issue of how to approach third party consent received significant attention during this project but ultimately remains unresolved. The difficulty is that each person with dementia and their respective families are likely to have different requirements and opinions regarding the handling of third party consent. People generally seem comfortable requesting informed consent from formal carers and regular visitors who are aware of an individual’s dementia diagnosis. However, it may not be practical nor appropriate to seek consent from a unexpected third parties, or in situations where the consent risks divulging information about the person with dementia that they may not wish others to be aware of. A facility should be provided with all ICT system to temporarily suspend, or switch off the system in circumstances where (a) the person with dementia and/or their carer does not want to have to seek consent from visitors to the home, or (b) the visitor does not wish to participate and therefore does not give their consent.

### 4.3.2 Privacy and surveillance

The informed consent process must clearly state the type of data that will be collected, stored, manipulated and visualised in the Dem@Care system, and how the security of this data will be protected. It must be clear who will have access to this data and how it will be used. Despite research protocols that expressly consider privacy concerns and the provision of sensor privacy options, the impaired cognitive status of the person with dementia does result in data collected in situations that they would not want to see captured; for example, in the bathroom. Researchers and clinicians need to be aware of this issue and additional safety nets need to be designed to prevent these situations from occurring. This may require the integration of automatic recording cut-offs when activity is detected in situations where privacy is likely to be compromised. System users also should be provided with the ability to delete unwanted data.

A risk of surveillance must be considered when people's daily activities are monitored. When this data is available to others (e.g. family carers) remotely, conflicts arise between the rights of the person with dementia and the wishes of their family carers to 'manage risk' or assure themselves of their safety, by monitoring them from a distance. It is unlikely that all family carers understand the ethical dilemmas inherent in this type of continuous monitoring. The motivation for using technology must be clearly articulated in order to appreciate the different ethical challenges that will arise, especially if the system benefits the carer more than the person with dementia.

### 4.3.3 Best interests of the person with dementia

Dem@Care and its associated @Lab protocol improves the assessment of autonomy in activities of daily living which is often difficult to assess in clinical practice since the only source of information is either the informal caregiver, who tends to underestimate certain capacities, or the person with dementia who often tends to overestimate his or her capacities, or may lack insight into their current levels of functioning. Particular consideration needs to be given to how best to confront people with dementia with their loss of functionality. It was ethically challenging to have this discussion when the person with dementia had a very different idea of his or her condition than the observed and recorded performance in the @Lab suggested. In some situations, the Dem@Care results had a positive impact as they enabled a discussion about the possibility of receiving some help at home, but in other situations, the person with dementia found the results very difficult to accept. It was important to manage this delicate situation with empathy and understanding to avoid overwhelming the person with dementia with their loss of function in the different life domains.

Dem@Care recognized the importance of including people with dementia and their caregivers in the co-design process, but new systems require new learning and familiarization. They also require testing and improvement, and technologies and sensors can and do fail at times. Each of these aspects increased stress and anxiety for system users, particularly if they thought it was something that they were doing wrong. Research projects that use new sensors and new technologies will face similar challenges, and distress can be alleviated in three ways: (1) assure the person with dementia and their carer that the fault is a technical one, (2) if the fault cannot be resolved immediately by the researcher, remove the sensor until the next visit making it clear that a technical check needs to be run, and (3) provide as needed, out of hours support, with an assurance that it is ok to call the researcher if any problem arises. Training periods were found to decrease initial anxiety and they were key to technology acceptance, as were high levels of ongoing support.

Although the evolving nature of a new system or new technology is explained to participants during the information and consent process, every effort should be made to ensure that stable versions of the system and sensors are deployed such that participant anxiety and distress can be minimised. Feedback should be easy to access, clear, and provided with a level of interpretation appropriate to each type of end-user. Specific care needs to be taken to ensure that feedback to people with dementia and their carers is presented in a clear and personally relevant way with the understanding that heightened awareness of their own situation and performance may in turn cause anxiety as decline may become more evident. Sensors should therefore only be introduced where there is a particular need and where the sensor provides an effective and acceptable solution for the person with dementia.

### 4.3.4 Risk of replacing or reducing human interaction

The @Lab pilots faced the challenge of using many different sensors to support the assessment process and this sometimes caused anxiety for participants, particularly those who were less comfortable with technology. The use of sensors will also raise anxiety for someone who is aware that they are in denial about their condition. They may fear that the system and the sensors will detect behavioural changes that they are not yet ready to face and that they would not have volunteered to the clinician themselves, and ultimately that they will be diagnosed with dementia which they are currently motivated to avoid. This anxiety can present as anger or frustration during the assessment process. It is important for the clinician to introduce each sensor and to clearly explain why each is useful and how they improve the diagnosis process. Furthermore, it must be underlined that a diagnosis will not be made on the basis of the sensor data alone; a diagnosis requires a qualified clinician to consider sensor data in combination with many other factors such as biomarkers and neuropsychological test. Finally, it is essential that time for discussion with the clinician is preserved and that this vital human interaction is never completely replaced in clinical practice.

In the home environment, there were times during the pilot evaluations when the researchers became aware that caregivers were experiencing significant levels of stress. This information was gleaned from conversations that took place during data collection and feedback visits and from psychometric tests that measured caregiver quality of life, stress and burden. In these situations, researchers were encouraged to spend more time talking to the caregiver about current issues and difficulties, rather than solely focusing on data collection and feedback. Participants were also encouraged to speak to their GP and/or other members of their clinical team. The feedback from carers and indeed from the participants with dementia highlights the importance of this face-to-face contact and the value they place on regular and extended opportunities to talk to someone about their situation.

### 4.3.5 Concluding remarks

The goals of AAL technologies are generally positive as they address enablement, empowerment, providing support for ADLs, and minimizing potential harm, such that they allow the person with dementia to maintain their independence for longer, but they must also preserve their rights to self-determination and control. A person-centred approach is needed when introducing technology in an ethical manner that ensures the best interest of the person with dementia. It should be recognised that there are certain needs for which technology is not a suitable solution [65]. Technology should not be seen as a ‘quick fix’ to psychosocial and societal problems [65, 66]. Person-to-person social interaction is important to people with dementia and family caregivers also value their caregiving roles. Technology should support and not replace human interaction and as such, the following questions must be addressed before it is deployed:

- Can technology provide a possible solution to this particular difficulty for the person with dementia?
- Does this technology provide the best solution, given that it potentially comprises the person with dementia’s privacy?
- Is the technology acceptable to the person with dementia in the first instance, and consequently to their caregivers?
- Does the technology play to the person’s strengths, or is it likely to place them under additional cognitive strain or emotional distress?

As Novitzky and colleagues [67] recommend,

> “*Researchers should bear in mind that the provisioning of technologies for PwDs is non-therapeutic , thus the justification of possible harms involved requires and outweighing amount of benefits to make the assistance of AAL technologies favourable.”*

# 5 General Conclusions

The World Health Organisation declared dementia a global health epidemic and a public health priority in 2012 [68]. There were 44 million cases of dementia in 2013 and this has been projected to rise to 135.5 million by 2050 [7]. Dementia has great personal, societal, and economic impacts. People with dementia start to lose their ability to live independently as the condition progresses, which can force them to withdraw from their active role in society, and eventually require daily assistance from formal and informal caregivers. The cost of dementia care surpassed $600 billion in 2010 and this is expected to rise by 85% by 2030 [8]. As yet, no effective cure has been found, but an earlier and more accurate diagnosis, followed by more effective personalised treatment, can improve the quality of life of people with dementia and their families.

The Dem@Care system provides an integrated solution for the remote monitoring, diagnosis, and support of people with mild cognitive impairment and dementia. It combines the use of multiple wearable and ambient sensors for the recognition of daily activities, extraction of lifestyle patterns and emotions, as well as the use of intelligent decision support mechanisms for the assessment and monitoring of a person with dementia's condition over time in various care settings. Feedback is provided to clinicians, people with dementia, and their formal and informal caregivers, in different forms and tailored to their respective needs.

The innovative data analytics and decision-making solutions provided by Dem@Care minimise subjectivity in current clinical diagnosis protocols and facilitate automated objective assessment of autonomy in instrumental activities of daily living in clinical settings (@Lab pilots in France and Greece).

> *"Real-life monitoring can lead to more accurate and more timely diagnosis of early stage dementia: Dem@Care has already provided critical diagnostic aid reliably and accurately discriminating 82% of health, MCI, and AD individuals."*
> [Professor Philippe Robert, University Hospital Nice, France].

Comprehensive and objective information on patterns of sleep, physical activity and stress for an individual over a period of time enhances clinical reasoning and improves the assessment and management of BPSD in residential care settings (@Nursing Home pilot in Sweden). The analysis of the strength and degradation of recurring behaviour patterns over time enables the formation of a comprehensive and objective picture of the individual's overall condition, which better informs the provision of appropriate treatment and care for people with dementia living at home (@Home pilots in Ireland and Greece).

> *"The information coming from the Dem@Care sensors demonstrates that it is possible to use this type of data to support individualised psychosocial interventions. This in turn should facilitate optimised person-centred care solutions for those living at home with dementia."*
> [Dr Louise Hopper, Dublin City University, Ireland].

However, the impact of Dem@Care in the home and nursing home environments is not as yet as convincing at that obtained in the diagnostic lab setting. Quantitative findings @Home and @NursingHome are descriptive in nature and based on very small numbers of participants, but preliminary qualitative findings have been presented that demonstrate benefits to people with dementia and their informal caregivers. It was also difficult to determine the extent to which the people with dementia, and in particular those with co-morbid depression and loneliness, benefitted from Dem@Care itself, or from regular visits by supporting clinicians and researchers, or most likely some combination of the two. Further trials are required in order to better investigate the potential impact of Dem@Care in the home and nursing home environments. Nevertheless, preliminary results are in a good direction.

From a technical perspective, Dem@Care has advanced the state-of-the-art in many research areas. Novel visual sensing algorithms have been developed for complex activity recognition from static and wearable cameras, supporting highly accurate real-time event detection and people tracking. In addition, intelligent machine learning and dynamic model adaptation solutions provide person-tailored situation interpretation and assessment, effectively handling behaviour variability. The advanced audio sensing analytics of Dem@Care are capable of reliably extracting sensible quantitative characteristics, indicative of the person's behavioural, mental and emotional state.

These diverse sensing methods are combined with lifestyle monitoring of daily physical objects and utilities by novel context-aware multi-sensor fusion solutions. Fusion provides intelligent decision making, coupling monitoring results with clinical and profile knowledge using semantically enriched vocabularies and ontologies. At the same time, intelligent event-driven mechanisms enable context-sensitive and personalised supportive feedback via flexible, adaptive visualisations of daily activities and personalised alerts, thus enabling scheduled problem checks and other automated interventions. Finally, using state-of-the-art protocols for security, extensibility and modularity, the Dem@Care platform enables secure integration with the most recent sensors and offers adaptability to each person's needs in terms of comfort, clinical needs, and areas of interest.

Future exploitation of the Dem@Care system is dependent on evidence from larger cohorts that support the personal and societal impacts discussed in this report. Robust technical performance of the system, and ease of use for all end-users, will be key to its acceptability and price levels must correspond with the benefits that Dem@Care can provide to each stakeholder group.

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# 7 Appendix A

As presented in the Initial Stakeholder Evaluation Report (D2.7), a range of measures were used to evaluate the impact of the Dem@Care system on the key stakeholder groups. These are summarised in the matrix in Table 2 overleaf. Concepts evaluated in the @Lab pilots were measured by CHUN in Nice and by CERTH in Thessaloniki. Concepts evaluated in the @Nursing Home pilots were primarily measured by LTU in Lulea with some additional inputs from a short @Nursing Home pilot in CHUN in Nice. Concepts evaluated @Home were measured by DCU in Dublin and by CERTH in Thessaloniki.

The pilot protocols, the psychometric measures, the expert interview schedules, and the acceptability and usability questionnaires have been described in the various deliverables from the Pilot Evaluation work stream (WP8). The final version of the Dem@Care system (Prototype 3 plus required bug fixes) was used as the basis of the full evaluation of the Dem@Care system. The detailed results of this evaluation are reported in detail in the Final Pilot Evaluation Report (D8.5).

Table 2. Matrix of evaluation measures for each of the key stakeholder groups.

| | **Person with Dementia** | **Informal Carer** | **Formal Carer** | **Clinician** |
|---|---|---|---|---|
| **Improved Diagnosis**<br>@Lab | Neuropsych battery<br>Diagnosis using Dem@Care | N/A | N/A | Acceptability<br>Q-Interview |
| **Independence**<br>@Home<br>@Nursing Home | Qol-AD[1]<br>DemQoL[1]<br>Bristol-ADL<br>Everyday CQ<br>Scale-OAR<br>NPI / NPI-NH<br>Dem@Care[2]<br>Acceptability<br>Q-Interview | CarerQol<br>RSS<br>PSS<br>Acceptability<br>Q-Interview | NH Obs<br>Acceptability<br>Q-Interview | Acceptability<br>Q-Interview |
| **Sense of Improvement**<br>@Home<br>@Nursing Home | RAPA<br>PA-Elderly<br>Pittsburgh SQI<br>Epworth SS<br>Insomnia Severity<br>GDS<br>DeJong Lonliness<br>Lubben Social<br>NPI-NH<br>Dem@Care[2]<br>Acceptability<br>Q-Interview | CarerQol<br>RSS<br>PSS Acceptability<br>Q-Interview | NH Obs<br>Acceptability<br>Q-Interview | Acceptability<br>Q-Interview |
| **Security/Safety**<br>@Home<br>@Nursing Home | Dem@Care Alerts<br>Acceptability<br>Q-Interview | Dem@Care alerts<br>Acceptability<br>Q-Interview | Dem@Care alerts<br>Acceptability<br>Q-Interview | Dem@Care alerts<br>Acceptability<br>Q-Interview |
| **Reduce Costs**<br>@Lab<br>@Home<br>@Nursing Home | Independence<br>Sense of improvement<br>Security/safety<br>Acceptability | Independence<br>Sense of improvement<br>Security/safety<br>Acceptability<br>Q-Interview | Independence<br>Sense of improvement<br>Security/safety<br>Acceptability<br>Q-Interview | Improved Diagnosis<br>Acceptability<br>Q-Interview |
| **Social Inclusion**<br>@Home<br>@Nursing Home | Independence<br>Sense of Improvement<br>Q-Interview | Independence<br>Sense of Improvement<br>Q-Interview | Independence<br>Sense of Improvement<br>Q-Interview | |

Note: CarerQoL, Carer Quality of Life Scale; DemQoL, Dementia Quality of Life Scale, Epworth SS, Epworth Sleepiness Scale; Everyday-CQ, Everyday Competence Questionnaire; GDS, Geriatric Depression Scale; NPI (NH), Neuropsychometric Inventory (Nursing Home); NH Obs, Nursing Home Systematic Observation; PA-Elderly, Physical Activity Scale for the elderly; PSQI, Pittsburgh Quality Sleep Index; PSS, Perceived Stress Scale; Q-Interview, Qualitative interview; QoL-AD, Quality of Life – Alzheimer disease; RAPA, Rapid Assessment of Physical Activity Scale; RSS, Relative Stress Scale; Scale-OAR, Scale of Older Adults Routine;

[1] Includes the proxy version of this measure

[2] Includes both problem and pattern identification in Dem@Care

# 8 Appendix B

Stakeholder testimony and opinions were gathered using qualitative semi-structured interviews and focus groups.

## 8.1 Qualitative data collection

Questions varied slightly depending on the type of stakeholder and the pilot setting (i.e. the home, nursing home or lab), but they were generally focused on addressing the key areas of personal impact for that stakeholder group. Evaluation of the Dem@Care sensors and interfaces was based on the QUIS-short version, a standardized questionnaire for user interface satisfaction [69] and the PUEU questionnaire regarding the perceived usefulness and ease of use [70]. Specific findings from each of the evaluations were presented in the Final Pilot Evaluation Report (D8.5).

### 8.1.1 Expert clinical evaluation of the clinician's interface in the home pilots

In order to evaluate the Dem@Care user interface satisfaction and the usefulness of the clinician interface for the home pilots, the QUIS-short version [69] and the PUEU questionnaire [70] were used.

- In Thessaloniki for the Greek home pilots, the clinical experts answered these closed-ended questionnaires in Likert scale. At the end they had to answer an open-ended question about the most positive and negative thoughts regarding the system.
- In Dublin for the Irish home pilots, all questions were presented in a focus group setting in order to generate wider discussion about healthcare professionals' perceptions of the potential for the use of Dem@Care for the management of dementia for those living at home with the condition.

### 8.1.2 Interview questions for the person with dementia living at home

The following questions should be used to guide the discussion with the person with dementia. The aim is to understand their perceptions and opinions of the system/sensors, their overall satisfaction with Dem@Care, and its ability to enhance their daily life.

- Overall, how did you find the system/sensors?
- Was learning how to use the system: difficult – easy?
- How useful was the system in helping with day-to-day life?
    - What did you find particularly useful?
    - What was not very useful?
    - Would you have liked more alarms or reminders?
    - Would you have liked more checklists or instructions on what to do?
    - Would you have liked more information about sleep, keeping active, …?

- Do you think you would continue to wear these sensors (or similar) to follow your everyday life?
- Do you think you would agree to installing cameras in your home to follow your everyday life?
    - If no … what are the motives for your reluctance?
- How useful was it having a researcher visit on a regular basis?
    - Which would you rate most highly, the researcher visits alone, the system alone, the combination of the researcher visits and the system?
- What changes would you like to see that would make the system more useful?
- If this system was available to you at a cost, would you be interested in it?
    - Up to what level of cost would be appropriate?

Sensor- and system-specific feedback was also gathered during the interview. In Ireland, questions were based on the System Usability Scale [27] and QUIS-Short version [69], while in Thessaloniki questions were based on the QUIS-Short version [69] and the PUEU questionnaire [70]. The wording of the questions was simplified and participants' responses could be recorded as free text if they were unable to provide Likert scale answers.

### 8.1.3 Interview questions for the carer in the home environment

The following questions should be used to guide the discussion with the informal caregiver. The aim is to understand their perceptions and opinions of the system/sensors, their overall satisfaction with Dem@Care, its ability to enhance the daily life of the person they care for, and its ability to enhance the carer's own day-to-day living.

- How was it for <name of person with dementia> to use the sensors/system alone?
    - Which features were easiest to use and why?
    - Which features were hardest to use and why?
    - What would need to change to make this more usable in a home setting?
- How did the (or could the) system help improve the autonomy of <name>?
    - What would need to change to make this better?
- In what ways did the sensors/system reduce the amount of care needed (or could you see care reducing if the full system was available in the future)?
    - Had a more complete system (with feedback) been available to you earlier, could it have delayed your need to cut back working hours?
- What were the benefits of taking part in this research from your perspective?
- What were the drawbacks?

Sensor- and system-specific feedback was also gathered during the carer interview using the same procedure as that used for the people with dementia.

### 8.1.4 Interview questions for formal caregivers in nursing homes

Given the time pressures on formal care staff, a form was designed to facilitate qualitative data collection in the nursing home environment. A copy of the form is presented below:

**Assessment of Usability** **Code**______________________________

This form will be used for collecting information for each participant that have a Dem@care sensorised system deployed in their room or as wearable sensors. The questions will be answered by the staff who is responsible for the care of the person

1) What is your general impression of the sensor technology used for this person?
   a. Was it easy or difficult to use the sensors in the support of this person?
   b. Were the sensors easy and comfortable to wear?
   c. How was the acceptability of the stationary sensors?
   d. Do you see any privacy or ethical issues for this user with the deployment of the sensors.

2) In what way could the deployment of the sensors support the user?
   a. Can you identify situation where they were helpful (please elaborate)
   b. Can you identify situation where they hindered (please elaborate)
   c. Situations where they made no difference. (please elaborate)

4) Were there any impact of the sensors and assistive technologies impact on the other residents in the nursing home? (Please elaborate)

5) How was the technical function of the sensor system?
   a. Technical stability (on individual sensors and on the system as whole)
   b. User-friendliness (of individual sensors and on the information screen)

### 8.1.5 Interview questions for people with dementia in the lab environment

During the @Lab inclusion period, participants were asked to fill out an Acceptability Questionnaire. A copy of the questionnaire is presented below:

Q1: All the tasks seemed:

- Hard (1) -> (10) Easy
- Stressful (1) -> (10) Pleasant
- To correspond to situations of your everyday life – Yes / No

Q2: On the whole evaluation, you found:

- The environment stressful – Yes / No
- The duration – Too Long / About Right

Q3: Using sensors during this evaluation:

- Put you under stress – Yes / No
- Affected what you thought of the evaluation – Yes / No

Q4: Generally, did you easily understand what was being asked of you? Yes / No

Q5: Did you understand what the evaluation was interested in finding out? Yes / No

Q6: Would you be willing to participate in this evaluation again? Yes / No

Q7: Would you agree to wear sensors to monitor your activities of daily living? Yes/No

- If yes, for how long? Permanently / One week / One Day / Occasionally
- If no, what are the reasons for your reluctance?

Q8: Would you agree to have sensors installed at your home to monitor your activities of daily living?

- If yes, for how long?
- If no, what are the reasons for your reluctance?

Q9: If information meetings about the sensors and how they are used were suggested to you, would this reassure you more about their use?

Q10: If the use of these sensors were prescribed by your doctor, would you accept it?

At the end of each diagnostic session, the clinician and the participant spent some time discussing the session. The participant was asked how they felt about the sensors and how they found the whole experience undergoing the @Lab protocol. The comments and quotes used in reporting @Lab findings were taken from a combination of the Acceptability Questionnaire responses and from clinician notes taken during the semi-structured debriefing sessions.

## 8.2 Qualitative data analysis

The interviews were transcribed intelligent verbatim. The transcripts were analysed using inductive coding analysis. This meant using open coding and deriving categories directly from the material [71-73]. Dialogue among researchers is highly valuable during the open coding process as it promotes the most likely interpretation of the data [72], so the analysis was performed by at least two researchers. The transcripts were read line by line to identify meaning units (such as words, sentences, or paragraphs that relate to the same meaning). Meaning units were then labelled with codes. Categories and sub-categories were then developed based on these codes. These were then assumed to represent the manifest content of the transcript [72] and anchor examples that best reflected their meaning were selected from across the transcripts.

## 8.3 Reporting qualitative findings

Qualitative results were reported using the derived categories in the Final Pilot Evaluation Report (D8.5). A further analysis was performed to group the categories and sub-categories into the high level themes required by this report; for example, Personal impact for the PwD (i) independence, (ii) sense of improvement, (iii) Security and Safety; Personal impact for the Carer (i) Independence, (ii) sense of improvement; Personal impact for the Clinician and formal care staff (i) Timely Diagnosis, (ii) Improvement in treatment and care.