The Personal and Societal Impact of the Dementia Ambient Care (Dem@Care) Multi-sensor Remote Monitoring Dementia Care System

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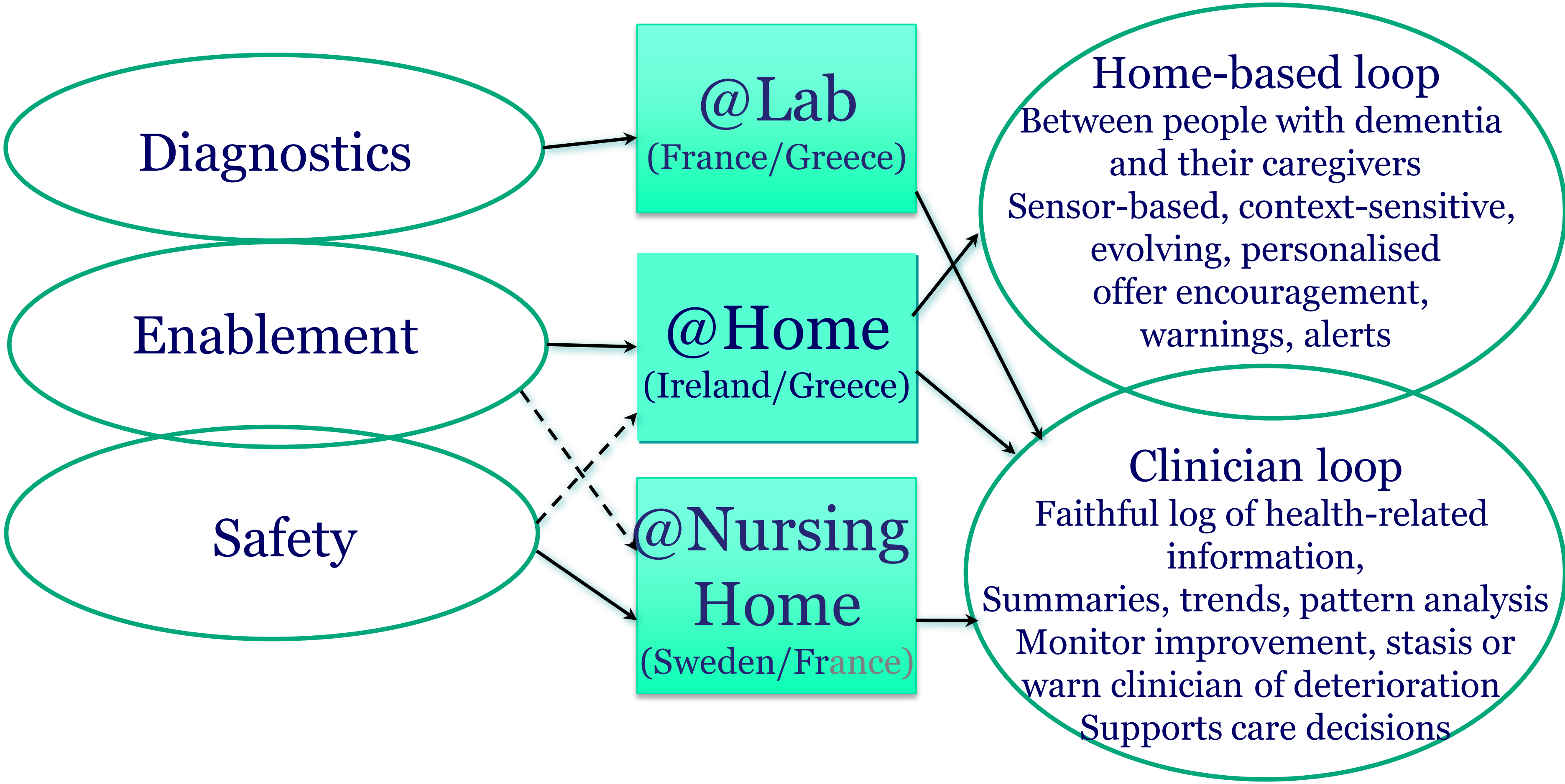
The Dem@Care Project



3 Themes

- Diagnostics
- Enablement
- Safety

3 scenarios

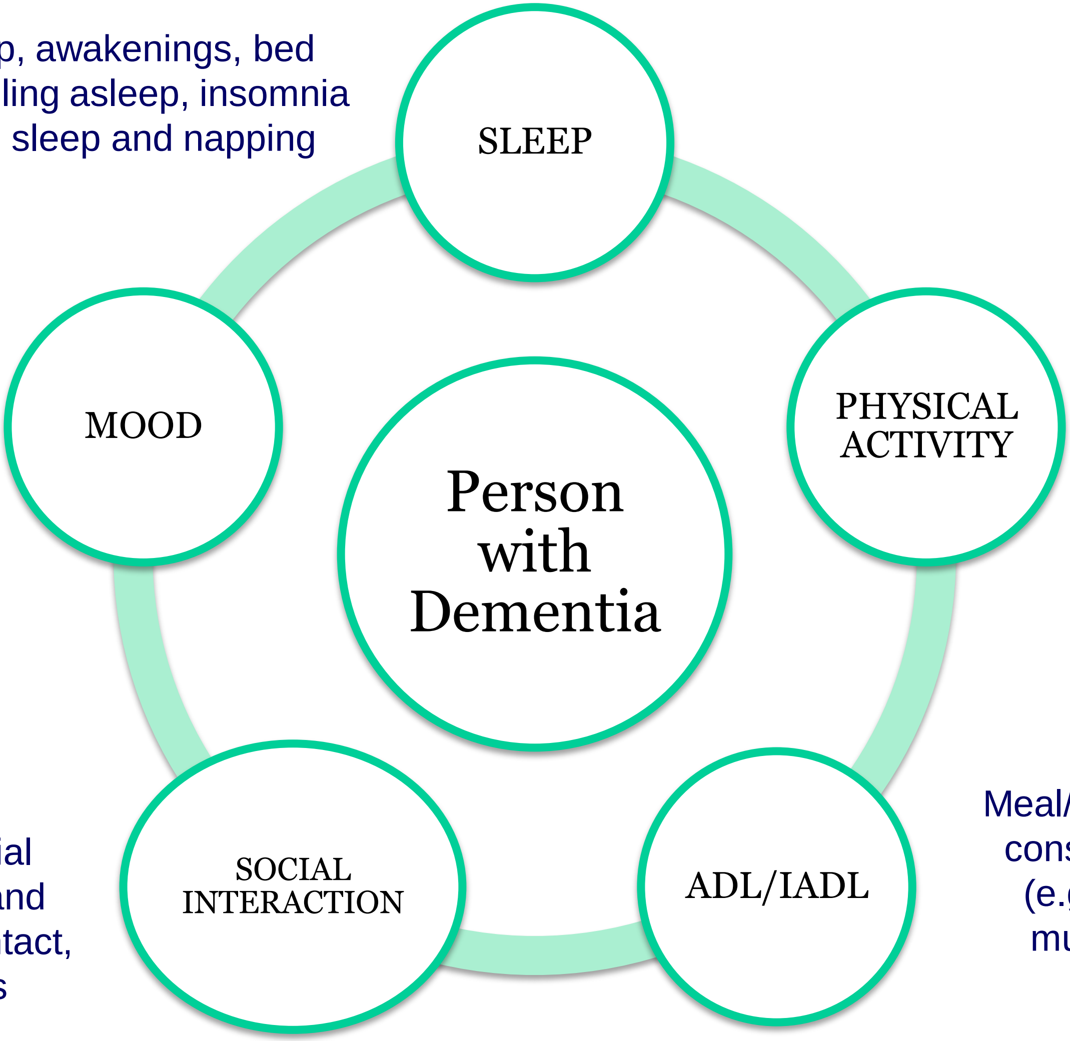
- @Lab (France/Greece)
- @Home (Ireland/Greece)
- @Nursing Home (Sweden/France)

2 loops of care

Home-based loop
Between people with dementia and their caregivers
Sensor-based, context-sensitive, evolving, personalised
offer encouragement, warnings, alerts

Clinician loop
Faithful log of health-related information,
Summaries, trends, pattern analysis
Monitor improvement, stasis or warn clinician of deterioration
Supports care decisions

Data Collection in Five Domains



Person with Dementia

SLEEP

Night time sleep, awakenings, bed exits, Difficulty falling asleep, insomnia onset, day-time sleep and napping

PHYSICAL ACTIVITY

Amount of physical activity in the home, outside the home, dedicated exercise, movement speed, distance travelled, activity intensity

ADL/IADL

Meal/Drink preparation and consumption, daily tasks (e.g. watch tv, listen to music, read, hobbies, chores)

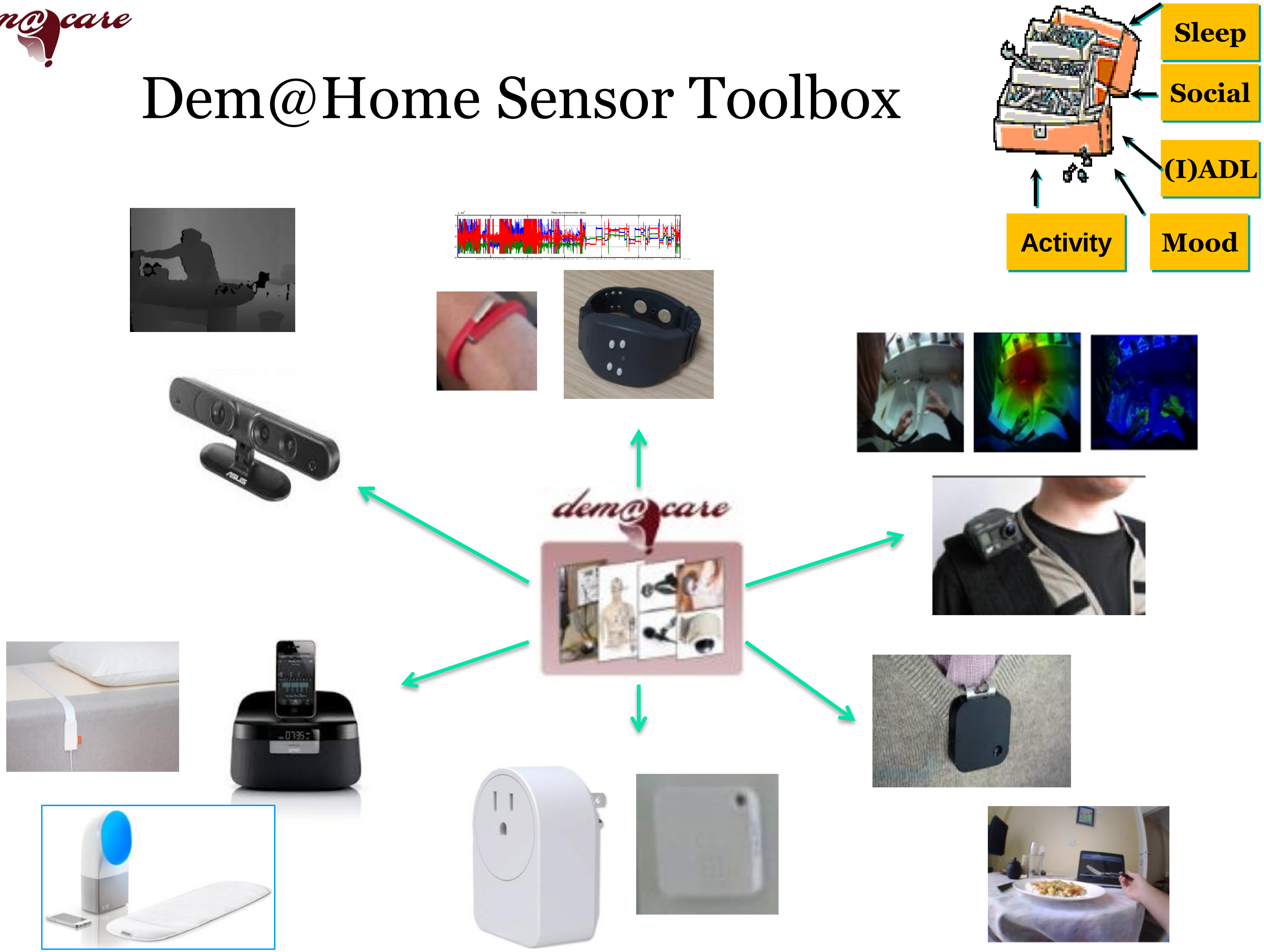
SOCIAL INTERACTION

Face-to-face social contact, initiated and received phone contact, speech analysis

MOOD

Observed behaviour, physical stress levels , speech analysis, subjective mood reporting

Dem@Home Sensor Toolbox



Sleep

Social

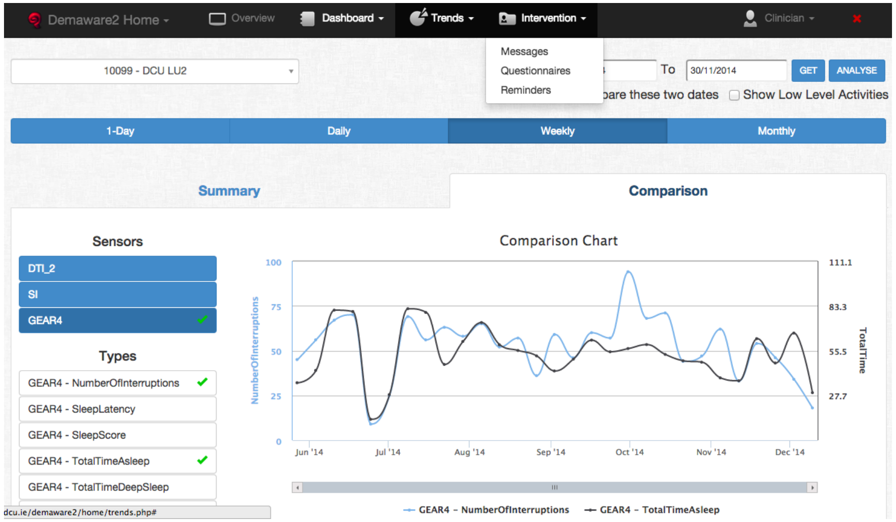
(I)ADL

Activity

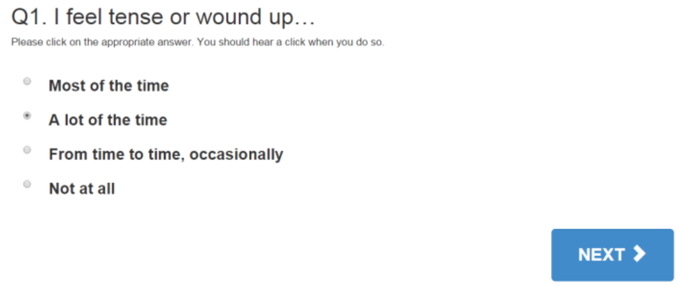
Mood

The Dem@Care System

- Clinician is able to monitor
    - Sensors recordings
    - Analysis results (e.g. completed activities) from the current or previous dates/periods



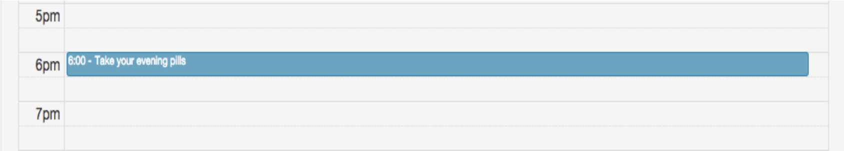
- Person with dementia and the carer are able to read messages-prompts-advice that come from
    - The System
    - Clinician


Q1. I feel tense or wound up…

Please click on the appropriate answer. You should hear a click when you do so.

- ○ Most of the time
- ● A lot of the time
- ○ From time to time, occasionally
- ○ Not at all

From	Message	Date
You have one new questionnaire! From Clinician		


5pm

6pm 6:00 - Take your evening pills

7pm

Dem@Care: Aims and Methodology

- Research Questions
  - @Lab: Can Dem@Care contribute to the assessment of dementia above and beyond traditional assessment methods?
  - @NH: Can Dem@Care effectively support nursing home staff to care for people with severe dementia (including BPSD)
  - @Home: Can Dem@Care optimise the functional status of the PwD and support their independence and autonomy

- Methodology
  - @Lab: Quantiative between group (Healthy, MCI, AD); *n*=380
  - @NH and @Home: Multiple case study design; *n*=13
  - @H: Multiple case study design; *n*=16

Personal and Societal Impact

- Four beneficiary groups
  - the PwD, informal caregivers, the clinician, and formal care staff
- Stakeholders
  - end-users, academics and professionals, and policy-makers

- Personal Impact: Quality of life (PwD/Carer)
  - Independence, Sense of Improvement, Security & Safety
- Social and Economic Impact: Builds from personal impact
  - Social inclusion, increased understanding of BPSD
  - Early diagnosis increases, staff costs reduce, at home for longer
- Advance technical, clinical, and ethical state-of-the-art

Personal Impact - People with Dementia

- Increased autonomy and independence in daily life
  - “*I feel kind of in control, do you know what I mean? In control of my day.*” [@H PwD]
- Sense of improvement across the five domains addressed
  - “*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*” [@H PwD]
  - “*I see my father is getting better! He is more active and walking a lot*” [@H Carer]
  - “*We are talking a lot more now … we are finding it easier to talk*” [@H Carer]
- Improved diagnosis and management of care
- Overall sense of improvement in subjective quality of life

Personal Impact – Informal Caregivers

- **Key carer concerns:** taking medication and eating properly, sleep, adequate physical exercise and stimulation
- Improvements for the person with dementia translated into improvements for their informal caregivers
  - *“It is a feeling of safety and relief that every caregiver of an elder person must have” [@H Carer]*
- Increased independence for some caregivers
  - *“I’m going away for the week in September …. He’s independent at the moment as we are trying to keep him as independent as long as we can… I used to give him his tablets, now he takes them himself” [@H Carer]*
  - But, carer independence was most related to the severity of dementia
- Overall sense of improvement in quality of life
  - *“My experience has been brilliant … I found it fantastic” [@H Carer]*

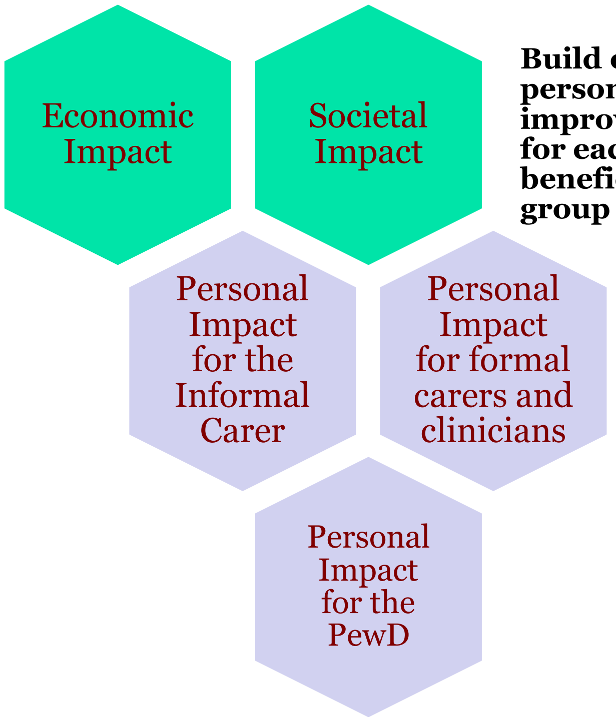
Personal Impact – Clinicians/Formal Carers

- Facilitate timely and accurate diagnosis while delivering efficiencies in terms of time and cost
  - Improved assessment/diagnostic procedures (incl differential diagnosis)
  - Improvements in clinical reasoning (@NH)
  - Reduction in observer bias

- More timely identification and better understanding of functional, behavioural, and emotion pattern changes
  - "*I was able to identify problems and issues* [e.g. REM sleep] *that otherwise would have been impossible*" [Clinician]

- Improved capacity and quality of care. Formal carers can:
  - develop and evaluate personalised interventions
  - better manage the care of the person with dementia
  - better manage the emotional and social disturbances of the Behavioural and Psychological Symptoms of Dementia (BPSD)

Societal Impact



Build on personal improvements for each beneficiary group

Difficult to evaluate the longer-term economic and societal outcomes but successful attainment of personal impacts for each stakeholder group will, over time, lead to these outcomes

- Economic: Cost efficiencies
  - Time savings (diagnosis/assessment)
  - Improved workflow, clinical reasoning, and intervention selection
  - Potential to reduce costs for national healthcare systems
  - Potential savings in the home environment – harder to quantify
- Social: Inclusion and awareness
  - Improved understanding of BPSD and reduction in social disturbance and therefore isolation @NH
  - Manage appointments and remain connected with life outside the home
  - Engagement with new social groups
  - Project dissemination activities

Scientific Impact: Advancing Technical SoA

- Novel visual-sensing algorithms
    - New approaches for perceptual analysis of egocentric video content
- Advanced physiological sensing and audio sensing
- Highly accurate real-time event detection and people tracking
- Creation of new knowledge structures, reasoning methods, rules, associations, and algorithms
    - Intelligent machine learning and dynamic model adaptation
- Novel context-aware multi-sensor, intelligent, event-driven feedback mechanisms
    - Adaptive visualisations of daily activities
    - Personalised alerts enabling scheduled problem checks and other automated interventions
- Integration and orchestration of sensing analysis and clinical applications

Scientific Impact: Advancing Clinical SoA

- Novel and holistic solution supporting all aspects of the clinical management of dementia
- Assessment and diagnosis
  - Improved early detection of dementia over and above traditional assessment methods alone – ability to detect subtle behaviour changes
  - Successfully differentiate between healthy, MCI and AD patients
  - Improved assessment of circumstances surrounding BPSD and their contribution to the expression of BPSD for an individual
- Treatment and care
  - Preventative care decision-making
  - Timely updating of care plans for the person with dementia
- Potential to support clinical trials
  - Selection and enrolment of participants
  - Support assessment in more ecologically valid environments

Scientific Impact: Advancing Ethical Debate

- Informed consent
  - High-tech nature of AAL may make it difficult for the PwD to fully understand what they are consenting to => Rolling consent
  - Ambient monitoring requires additional third party consent – no agreement in the literature as to how this should be handled
- Privacy and surveillance
  - Impaired cognitive status does lead to situations where data is captured that the PwD would not want to be captured
  - Risk of surveillance when monitoring ADLs or monitoring off-site
  - Carers do not always understand the ethical implications
- Best interests of the person with dementia
- Risk of replacing or reducing human interaction
  - Discussion time with clinicians needs to be preserved
  - Importance of therapeutic face-to-face contact highlighted @H

Conclusions

- Value of objective ongoing assessment
    - Analysis of sensor level data shows promising results although the real value of the Dem@Care system is the ability to:
        - *Triangulate data from various sensors measuring varied domains*
        - *Identify improvement, stasis, and/or deterioration over time*

- Supports that enable Dem@Home use
    - Easy to use sensors, data transfer, and automated feedback
        - *Caregiver is still required as primary source of support*
        - *Clinician needs to make the effort to ensure that people understand how ICT can and may not help, and that informed consent is given*
    - Importance of well-supported training periods
    - Importance of personal interaction with the clinician (or researcher)
    - Perceived benefits must be stronger than the perceived effort to use the technology

Conclusions

- Personal impacts found for all beneficiaries and stakeholders
  - Value of objective ongoing assessment/triangulation of data
    - *Improved clinical assessment of a person's cognitive, functional, and emotional status in a familiar environment*
    - *Supports ongoing monitoring of improvement, stasis, or decline*
  - Individualisation of interventions and treatment plans
    - *Improvements for person with MCI/dementia based on feedback and monitoring*
  - Potential for increased carer independence

- Advancement of technical, clinical and ethical state of the art

- But, difficult to evaluate economic and social impacts as:
  - Not all projects include a health economics element
  - Projects typically don't run for long enough (esp. development projects)
  - Need to develop short-term metrics that we know deliver benefits in the longer-term

dem@care

Thank you for your attention

For further information:

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