



Dementia Ambient Care: Home-based monitoring and enablement of people with dementia

*Dr Louise Hopper, Dr Eamonn Newman, Rachael Joyce,
Prof. Alan Smeaton, & Dr. Kate Irving
Dublin City University (DCU), Ireland*

*9th Panhellenic Conference on Alzheimer's Disease and Related Disorders and 1st
Mediterranean on Neurodegenerative Diseases, 14-17 May, Thessaloniki, Greece*

Presentation Outline



- Dem@Care @Home Pilots in Ireland
 - @Home Aims and Methodology
 - Lead User Case Study: Sean
 - Cognitive Rehabilitation Case Study: George
- Key findings from Dem@Care @Home
- Conclusions

@Home: Aims and Methodology



- Research Questions
 - Is the system acceptable in the home, is it non-intrusive, and useful to people with dementia and their families?
 - Can the system optimise the functional status of the person with dementia as operationalised in the 5 domains?
 - How autonomous and independent is the person with dementia and can the deployment of this system support this autonomy?
- Multiple case study design, person centred, co-design
 - Lead user pilot case study for 18 months
 - Additional pilots with increasing numbers of participants
 - *Supporting Cognitive Rehabilitation Interventions (n=6)*

Lead User Case Study: Recruitment Protocol



- Person living at home with early dementia - family caregiver
 - Initial semi-structured functional assessment interview
 - *General questions to determine if there are concerns in an area*
 - *If yes, proceed to psychometric measures; If no, move to next domain*

Sleep	PSQI, Epworth Sleepiness Scale, Insomnia Severity Index, Morningness - Eveningness Questionnaire, Scale of Older Adult's Routine
Physical Activity	Rapid Assessment of Physical Activity, Physical Activity Scale for the Elderly
Eating / IADL	Bristol ADL Scale (proxy), Everyday Competence Questionnaire, Mini-Nutritional Assessment
Mood	Geriatric Depression Scale
Social Interaction	Lubben Social Network Scale, De Jong Loneliness Scale

Lead User Case Study: Sean and Catriona

(pseudonyms)



- Sean (Age 58 at initial consent) and Catriona are married.
- They with Sean's mother in their own home outside Dublin. They have two dogs.
- Sean was a carpenter and Catriona works 4 days a week in administration.
- At the start of the study, Sean was just post-diagnosis.
- Sean is active and independent and has comorbid epilepsy, which is being successfully managed pharmaceutically.
- They have previously been involved in research with the DCU team, using the SenseCam technology to explore lifelogging.



- Sean's mother is not currently aware of his diagnosis.

Lead User Case Study: Assessment



Domain	Needs	Sensors
Sleep	PSQI score of 6 = pathological sleep issues Duration and latency good; disturbance, efficiency, overall quality poor	Gear4 Sleep Clock DTI-2 Actigraphy Bracelet
ADL / IADL	While general eating, cooking and chores are no problem for Sean, Catriona indicated that certain tasks may need support (CD Player)	Wearable Go Pro video Ambient video camera
Physical activity	No issues detected, although Sean indicated interest in having support in this area	DTI-2 Actigraphy Bracelet
Socialising	No issue detected, although both felt there may be a benefit from support in this area	Periodic psychometric measures
Mood	No issues detected	Periodic psychometric measures

Lead User Case Study: ADL / IADL

dem@care

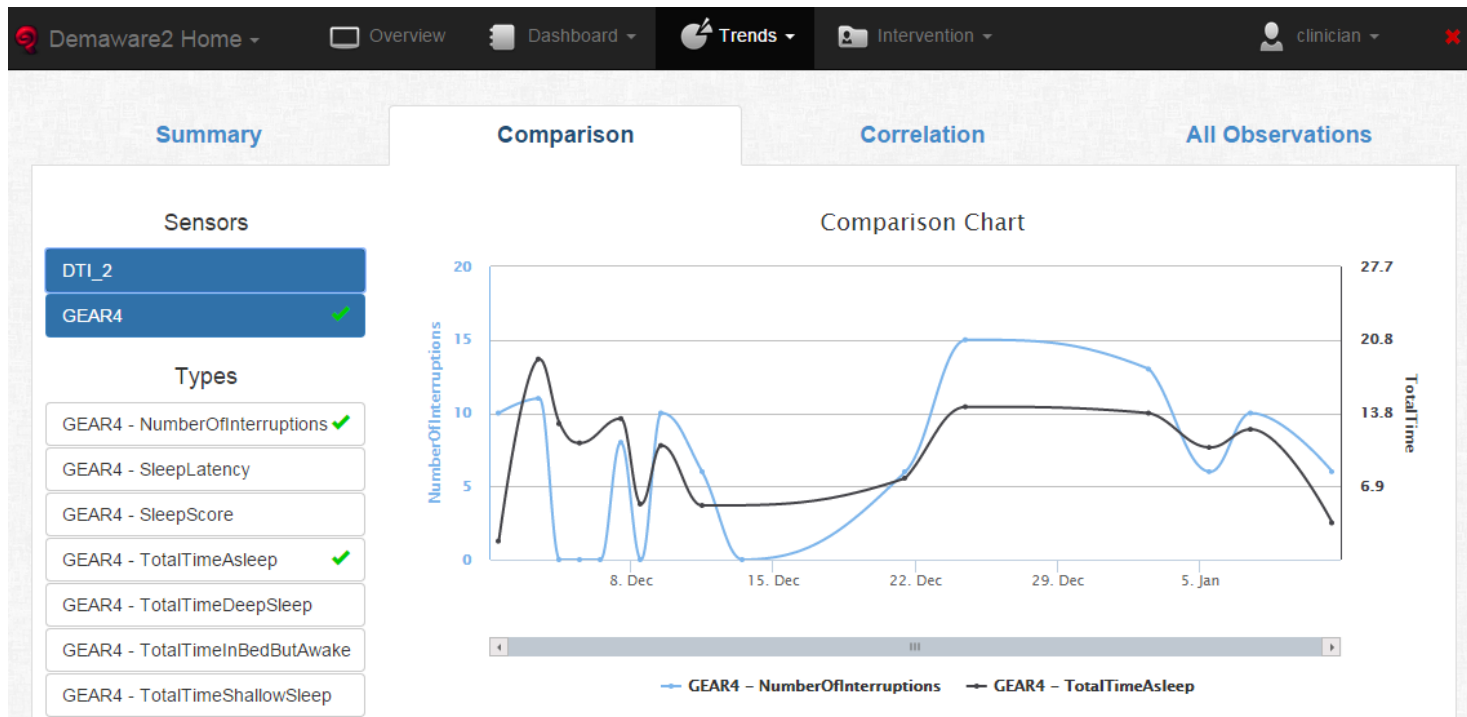
- Catriona laid out the jacket/camera with Sean's clothes every morning
- Most successful data capture was for activities that formed a natural part of Sean's day
 - Making breakfast, tea, watering plants, feeding birds
 - Capturing specific activities like 'playing a cd' were not successful unless they took place under the direction Catriona or the researcher
- Over 100 hours of data; 4.33 were manually annotated to train location, activity, and object algorithms
 - Initial models show promising accuracy levels
 - Feed birds (95.98%), Water plant (85.5%), Talk on phone (74.7%), Prepare drug box (49.7%), Breakfast (45.6%), Meal (46.98%), prepare tea (39.1%)



Lead User Case Study: Sleep

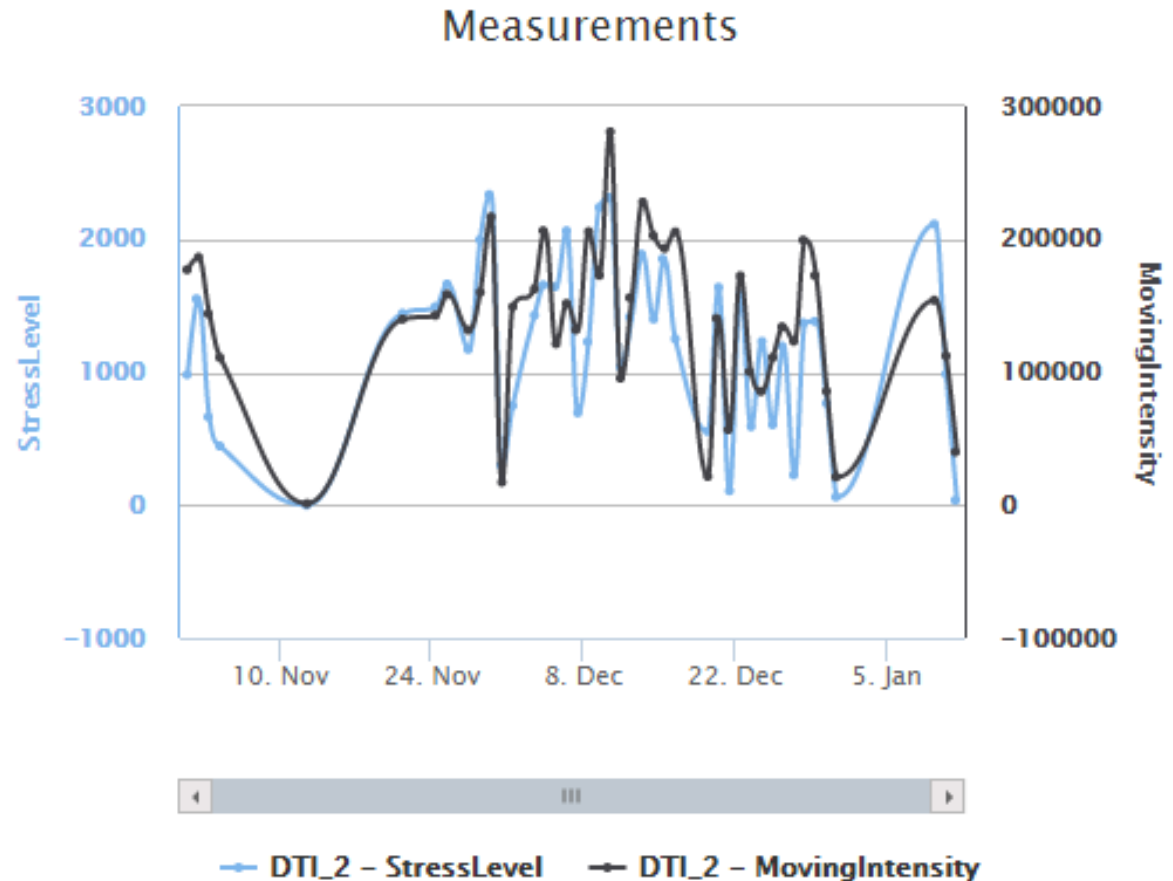


- 556 days deployment; 436 days of usable data
- Some disruption in sleep duration and sleep interruptions evident on a day to day basis but very stable patterns over time
- Clear periodicity – higher interruptions on week day mornings

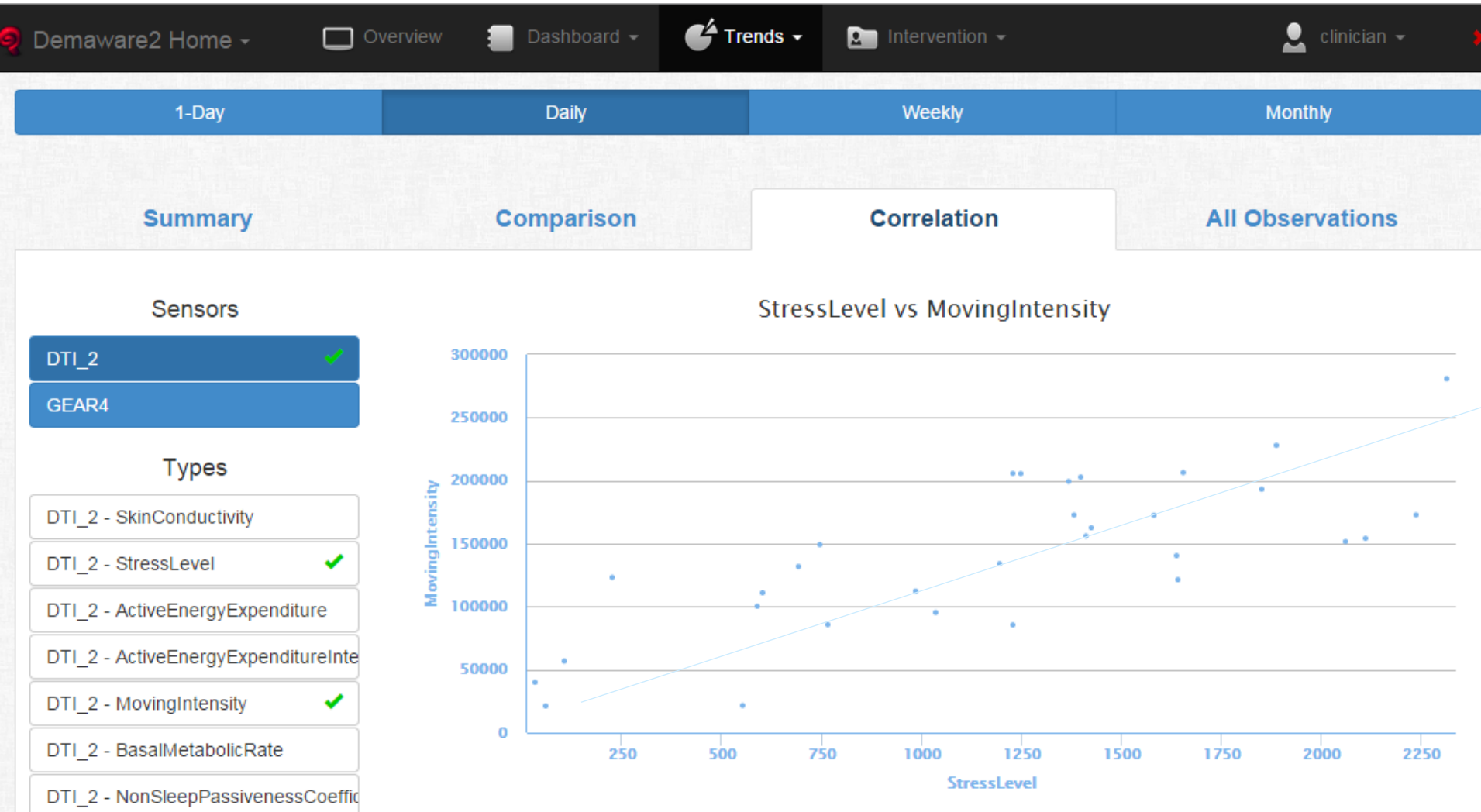


Lead User Case Study: Actigraphy

- 556 days deployment; approximately 450 days usable data
- Within day variation in activities (more active in the mornings)
- Stress levels generally match activity levels, although there were some exceptions that needed further investigation



Lead User Case Study: Actigraphy



Lead User Case Study: Data Comparison



Supporting Cognitive Rehabilitation (CR)



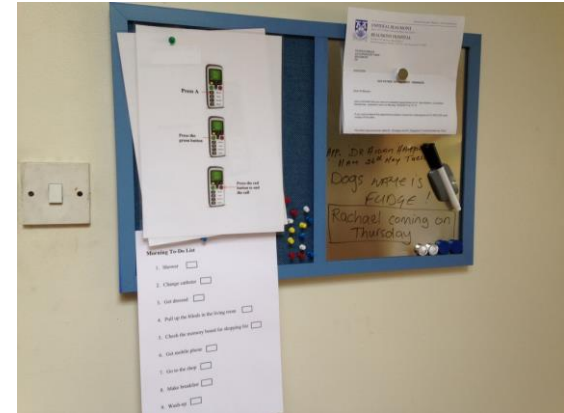
- CR refers to an individualised approach for people with dementia aimed at preventing or reducing excess disability and maximising engagement in activity and social participation, thereby improving quality of life (QoL) and well-being (Clare, 2008)
- Aims to tackle everyday manifestations of cognitive impairments that are important to the person with dementia and to their family (Clare, 2008; Wilson, 1997, 2002).



Supporting Cognitive Rehabilitation (CR)

- “Simple” cognitive aids
 - Memory Boards
 - Checklists and Routine Lists
 - Signs
 - Diaries

- These aids have been found to be very effective, but there great potential to harness technology in these areas
 - Dementia Clocks
 - Medication Reminders
 - Lost Item sensors / Alarms



Dem@Care Cognitive Rehabilitation Intervention



- The intervention is being delivered to 6 individuals with mild-moderate dementia
- Led by a therapist with an appropriate background (e.g. nursing, psychology, occupational therapy).
- Between 12-14 sessions; 90 – 120 minutes each
- Multi-disciplinary team meetings are held during the course of the intervention
- 5 out of 6 interventions have begun

CR Case Study: George

(pseudonym)



- Age 77 with mild-moderate Alzheimer type dementia
- Everyday difficulties:
 - Unable to use a new mobile phone
 - Forgetting to do certain things during the day
 - Fear of losing independence / being “locked up”
- CR Goals:
 - To be able to use a mobile phone and to remember to bring it with him when he leaves the house
 - To maintain his independence (remember the things he has to do in the morning, be able to cook for himself, remember to take medication)
- Dem@Care Support: Sleep, Wearable camera (GoPro), Audio

CR Goal : Using a phone



- **Goal 1:** To be able to use a mobile phone and to remember to bring it with him when he leaves the house

- **Learning to use the mobile phone**

- Strategies:

1. Simple to use mobile phone; four speed dials for calling important people
2. Phone instructions
3. 2 x practice sessions per week (45 mins)



To call Daniel:



Press the green button



Press the red button to end the call



CR Goal : Maintain Independence



- **Goal 2:** To maintain his independence (remember the things he has to do in the morning/self-care, be able to cook a meal, remember to take medication at night)
- **Remember the things he has to do in the morning**

➤ Strategies:

1. Morning “to-do” list – spaced retrieval & cueing methods used to help PwD1 become accustomed to using the “to-do” list

Morning To-Do List	
1. Shower	<input type="checkbox"/>
2. Change catheter	<input type="checkbox"/>
3. Get dressed	<input type="checkbox"/>
4. Pull up the blinds in the living room	<input type="checkbox"/>
5. Check the memory board for shopping list	<input type="checkbox"/>
6. Get mobile phone	<input type="checkbox"/>
7. Go to the shop	<input type="checkbox"/>
8. Make breakfast	<input type="checkbox"/>
9. Wash-up	<input type="checkbox"/>

CR Goal : Maintain Independence

dem@care

The screenshot displays the 'Demaware2 Home' interface. At the top, a navigation bar includes links for Overview, Dashboard, Trends, and Material, along with a user profile 'lu2'. The main content area features a vertical timeline from 9am to 8pm. Two medication reminders are visible: '10:00 - Take you morning pills' and '8:00 - Take your evening pills'. Below the timeline, an 'Inbox 0' section shows a notification: 'You have one new questionnaire! From Clinician', which is circled in red. A 'Take' button is located to the right of the notification.

From	Message	Date
	You have one new questionnaire! From Clinician	

Dem@Care Questionnaires



Demaware2 Home ▾ Overview Dashboard ▾ Trends ▾ Material ▾ DCULU2 ▾

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

NEXT ➔

Goal 3 : Cooking a Meal

- **Cooking a meal**
- **Strategy**
 - Weekly practice cooking a meal (with wearable camera)
- **Data analysis**
 - kind of support needed (e.g. confusion over which pot to use, quantites of food)
 - Facilitate the development of cooking instructions



Key Findings from @Home Pilots



- Recruitment difficulties unless combined with intervention
- Initial anxiety regarding sensor use (importance of training)
 - General concern about “doing something wrong”; “breaking” the sensor
 - Need to balance the idea of co-design and the introduction of an incomplete system with a person with dementia
- CR therapists concerned that sensors would increase demands on the person with dementia and heighten carer stress
 - However, sensors are working well when used “in session” and with direct therapist support
- The suitability of deploying sensors for the first time with someone in the later stages of dementia

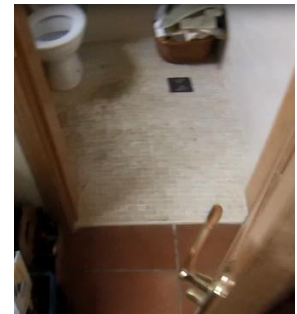
Informed Consent



- High-tech nature of AAL may make it difficult for the person with dementia to fully understand what they are consenting to
 - Rolling informed consent recommended
- Ambient functioning means that additional informed consent is needed from co-habitants
 - Experience suggests that this is generally achievable
 - Consent from other third parties (e.g. visitor to the home) is more difficult
 - No clear recommendation exists

Privacy

- The impaired cognitive status of the person with dementia does lead to situations where data is collected in situations that they would not want to see captured
 - Sensor 'privacy' options can be forgotten
 - Research protocols can be forgotten
- Researchers need to be aware of these issues
 - Develop additional safety nets in home environment
 - Provide a means to delete unwanted data



Surveillance

- Risk of Surveillance when monitoring ADLs
 - Determine which activities to monitor
 - What constitutes ‘normal/abnormal’ function?
 - Hofman (2013) asks if normality be defined in a heterogeneous population?
- Continuous ‘monitoring’
 - Has been requested by carers
 - These technologies do exist
 - Pose significant ethical challenges
 - NOT the purpose of Dem@Care



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
 - identify improvement, stasis, and/or deterioration over time

Supports the enable Dem@Care use:

- Easy to use sensors, data transfer, and automated feedback
 - Caregiver is still required as the primary source of support
- Importance of well-supported training periods
- Importance of the interaction with the therapist

Thank you for your attention



For further information:

www.demacare.eu

louise.hopper@dcu.ie

Funding Acknowledgement:



The research leading to these results has received funding from the European Community's **Seventh Framework Programme** (FP7/2007-2013) under grant agreement 288199



This project is funded by the European Union

Dem@Care Consortium partners

