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

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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

### Assessment Areas and Measures

<table>
<thead>
<tr>
<th>Domain</th>
<th>Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleep</td>
<td>PSQI, Epworth Sleepiness Scale, Insomnia Severity Index, Morningness - Eveningness Questionnaire, Scale of Older Adult’s Routine</td>
</tr>
<tr>
<td>Physical Activity</td>
<td>Rapid Assessment of Physical Activity, Physical Activity Scale for the Elderly</td>
</tr>
<tr>
<td>Eating / IADL</td>
<td>Bristol ADL Scale (proxy), Everyday Competence Questionnaire, Mini-Nutritional Assessment</td>
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<tr>
<td>Mood</td>
<td>Geriatric Depression Scale</td>
</tr>
<tr>
<td>Social Interaction</td>
<td>Lubben Social Network Scale, De Jong Loneliness Scale</td>
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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

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

- 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

1-Day

Daily

Weekly

Monthly

Summary

Comparison

Correlation

All Observations

Sensors

DTI_2

GEAR4

Types

DTI_2 - SkinConductivity

DTI_2 - StressLevel

DTI_2 - ActiveEnergyExpenditure

DTI_2 - ActiveEnergyExpenditureInte

DTI_2 - MovingIntensity

DTI_2 - BasalMetabolicRate

DTI_2 - NonSleepPassivenessCoeff
Lead User Case Study: Data Comparison

Comparison Chart

- DTI_2 - StressLevel
- GEAR4 - NumberOfInterruptions
- GEAR4 - TotalTimeAsleep

Sensors
- DTI_2
- GEAR4

Types
- DTI_2 - SkinConductivity
- DTI_2 - StressLevel
- DTI_2 - ActiveEnergyExpenditure
- DTI_2 - ActiveEnergyExpenditureInter
- DTI_2 - MovingIntensity
- DTI_2 - BasalMetabolicRate
- DTI_2 - NonSleepPassivenessCoefficient
- DTI_2 - PhysicalActivityLevel
- GEAR4 - NumberOfInterruptions
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)
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](image)
CR Goal: Maintain Independence
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
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, quantities 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:
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Dem@Care Consortium partners

[Logos of various partners]