EMPOWERMENT OF PEOPLE WITH DEMENTIA AND THEIR CARERS: BIG DATA AND MACHINE LEARNING TO THE RESCUE?

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Dementia in the UK and Surrey

National UK level (Source: *UK Alzheimer's Society*).

- 850,000 people in the United Kingdom currently live with dementia, and these numbers are set to rise to over 1,000,000 by 2025.

- Care needs in dementia are both complex and individualistic. Informal (unpaid) care dominates and carer burden is a significant ongoing issue.

- Dementia costs the UK economy over £26 billion a year, more than the costs of cancer, heart disease or stroke.

- Dementia is a Key Priority for the UK Government as set out in the Prime Minister’s challenge on dementia 2020.

Local setting of Surrey (Source: *local NHS statistics*)

- In Surrey and North East Hampshire we have a population of ~1,000,000 and of these 16,801 are estimated to have dementia.

- 55% of those on the dementia register across Surrey and NE Hants are admitted to hospital each year.

- 20% are frequent users of acute hospital services.
New 'dementia atlas' reveals disparity in care across England

Atlas shows care review performed for less than half of patients in some parts of country but for nine out of 10 in others.

Source: https://shapeatlas.net/dementia/
Our collective intervention is termed; **Technology Integrated Health Management (TIHM)** for dementia.

**Population**
- 1400 people to be recruited into a **Randomised Controlled Trial**, 700 people with dementia and 700 carers
  - Confirmed diagnosis of mild to moderate dementia
  - Someone providing significant support

**Intervention**
- Domiciliary IoT intervention for people with dementia and their carers.

**Comparison**
- Standard care versus standard care plus TIHM (350 dyads each).
Primary outcome

- Hospitalisations and health service use costs

Secondary outcomes
(people with dementia, carers and professionals)

- Quality of life
- Falls
- Behavioral symptoms
- Activities of daily living
- Carer distress
- Admission to care homes
- Participant and professional experiences of IoT use
TIHM for dementia: architecture

- Family member/Care giver
- Healthcare professional
- Monitoring portal
  - Continuous monitoring and observation data produce real-time insights and alerts
- IOT TEST BED CLOUD
  - Trust
  - Secure
  - Dependable

Inputs:
- Tablet
- Smart phone
- Medication
- Temperature
- Blood pressure
Which technologies will we be using?

Learning what is normal for you....

Combining information sources....
“Each single data item is important.”

“Relying merely on data from sources that are unevenly distributed, without considering background information or social context, can lead to imbalanced interpretations and decisions”
**Definitions....**

**Empowerment:**
Make an individual stronger and more confident, especially in controlling their life and claiming their rights.

**Big data:**
Large dataset which can be analysed computationally to reveal patterns and trends.

**Machine based learning:**
The ability to learn without being explicitly programmed....
Case Study: Margaret and David

David, 73, has early stage dementia and high blood pressure. Margaret with assistance from family is helping look after David.
Involvement of People with dementia and their carers

In our TIHM study we will explore;

**Qualitative measures**
- Previous use of assistive health technologies
- Diaries of use
- Barriers and facilitators in the use of IoT technology
- Subgroup analyses

**Quantitative measures**
- Device usage, utility of information collected
- Technology acceptable and attitudes
- Health service utilisation
Key challenges and opportunities

- People with dementia and carers
  - Usability and security
  - Not adding to ‘treatment burden’

- Health and social care professionals
  - Efficient use of available resources
  - Integration into normal working practice

- Healthcare commissioners
  - Scalability
  - Reduction in other NHS use
Summary

- **Machine based learning** and **Internet of Things (IoT)** interventions have the potential to be used to:
  - help identify patterns of behaviour for people with dementia in a real time basis.
  - develop a database of use for clinical decision making and resource allocation within the field of dementia
  - test the viability of a community based model of care with the support of technology
  - improve the quality of life and enhance a sense of empowerment for people with dementia and their caregivers

Our results are expected in Spring 2018!
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