Co-designing Technology for Better Dementia Care

Background

- More than 55 million people worldwide are living with dementia
  - 10 million new cases diagnosed each year
- An estimated 64,000 people are living with dementia (PLwD) in Ireland
  - Expected to rise to 150,000 by 2045 (HSE)
- For every person with dementia, it is estimated that three others support their care
- Informal carers (ICs) make up 6% of the Irish population

Societal Consequences

- Diminished quality of life and loss of independence

- Family members bear additional emotional and financial burdens

- Costs of EUR2 billion annually in Ireland

Dementia Care Models

- National healthcare systems are increasingly shifting towards a *community care model* for dementia

- Emphasis on *high-quality home care services* that enable PLwD *to remain in their homes for as long as possible*

- Most technologies focus on *safety* rather than empowering PLwD to engage in care planning

There is an acute need, which technology can potentially fulfil, to provide proactive support to PLwD and their ICs

People with dementia should be at the centre of care decisions, with a shift to empowered self-management facilitated by appropriately designed technology

Our Aims

Co-design a digital health technology platform to support people living with MCI and early-stage dementia to self-manage their health and wellbeing, with support from those who care for them

Ensure this technology platform also supports family carers in providing care, whilst also looking after their own health and wellbeing

Understanding Experiences, Challenges, Needs

- Interviews, focus groups and co-design sessions with 170 stakeholders
  - People living with age related cognitive impairments
  - Informal carers
  - Healthcare professionals
  - Staff from dementia charities

Gaps identified

- Lack of timely diagnosis

- Delays in accessing supports that could slow progression

- Many services geared towards older adults and not for those with early onset dementia

- A lack of formal, integrated care plans for homecare

- The needs of informal carers are poorly understood, particularly regarding education and support for their own wellbeing

Proposed solution

- Technology can be used as an early-stage intervention to fill the gap in the delayed provision of services

- Solution focused on:
  - Maintaining a sense of purpose and identity
  - Delaying progression by delivering relevant interventions and content at the right time

- A co-design methodology to understand the unique needs and preferences of PLwD and their ICs

What should this technology be / do?

Co-Design Workshops

User Requirements from Co-Design

Requirements
One structured care plan the PLwD that all stakeholders can contribute to and access
A care plan is also needed for ICs
Continuous, easily accessible orientation cues (including time, date, location and identity of familiar people)
Set goals in relation to activities and interventions and support tracking and completion
Include support for engaging in meaningful activities and suggesting replacement activities
Education is required on how to live well with dementia - oganise by stage of dementia

User Requirements from Co-Design

Requirements
There is a need to support psychological wellbeing
Support engaging in physical activity
Support social interaction with peers
PLwD need support with managing additional co-morbidities
Sign-post to available services
Sign-post to available assistive technologies and support their use

Feature / Intervention Requirements

- Scheduling / calendar
- Education, information, signposting to services
- Psychological wellbeing
- Cognitive rehabilitation
- Meaningful and stimulating activities
- Informal carer training
- Engage in physical activity
- Set and track intervention goals
- Social interaction
- Heath and wellbeing monitoring and management

Potential for Artificial Intelligence

- Personalized support - Adapt communication, reminders and care recommendations to each individual's needs and preferences.

- Cognitive assistance – provides orientation cues, memory prompts, and help with daily tasks in natural, conversational ways.

- Information simplification - simplify complex information into clear, accessible language with visuals or summaries.

- Emotional and social engagement – AI companions can reduce loneliness through conversation, reminiscence, and tailored meaningful activities.

More Information and Collaboration Opportunities

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