# cutive Summary



## Digital technology to support people living with dementia and carers

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### Digital technology to support people living with dementia and carers

#### **Executive Summary**

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#### 3 May 2022

This report presents independent research funded by the National Institute for Health and Care Research (NIHR) Policy Research Unit in Older People and Frailty. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Policy Research Unit Programme Reference Number PR-PRU-1217-21502

The full report with references is available <u>here</u>.

<sup>&</sup>lt;sup>1</sup> Our thanks also to Paul Freddolino (Michigan State University), Matthew Lariviere (University of Bristol) and David Sharp (Dementia Research Institute, Imperial) for helpful suggestions.

Helping people living with dementia and their carers to live well has been the core policy goal since England's first national strategy in 2009. The *Prime Minister's Challenge on Dementia* 2020 further emphasised consistent access, care and standards in delivering the best services and innovation. Digital technology has the potential to help deliver better and more equitable services for people living with dementia and their carers, although evidence-based policy direction and commissioning are needed to realise such a potential.

This DHSC-commissioned report summarises findings from a rapid evidence review on digital technologies that support people living with dementia and carers at home and in care homes, to answer the following questions:

- What technologies are being used to support independence and safety among people living with dementia at home and in care homes?
- What are the cost benefits and savings for provider organisations and the NHS of using the technology?
- What are the barriers to scaling the technology?

We discuss current research evidence on effectiveness, cost and cost-effectiveness of digital technologies in supporting people living with dementia and carers to live well, with comments on their technology readiness, and describe the main barriers to scaling up.

#### Findings on effectiveness

- A. Technologies used by people living with dementia
  - Although assistive technology and telecare (ATT) are more ready (Technology Readiness Level (TRL): validation stage), there is no evidence of effectiveness.
  - We found some evidence for virtual care support (TRL: production stage) on carer burden, depression and sense of competence, mainly coming from a US trial ('FamTechCare') of a video-based intervention that provides tailored care strategies to co-resident carers of people living with dementia.
  - There are suggestions that applying mobile technologies may be effective in supporting people living with dementia in self-care and daily activities (TRL: production stage), although these technologies currently tend to support more basic (physiological and safety) needs only, and with little effect on higher-level human and psychological needs.
  - Prompting and sensing systems (e.g., Development of Responsive Emotive Sensing System, DRESS) are at various TRL stages. We did not find any evidence on effectiveness yet.
  - Very preliminary evidence suggests the general use of tablets (TRL: production stage) independently by people with early-stage dementia may have an effect on carer relief.
- B. Technologies used with people living with dementia
  - Touchscreen technology-based interventions and activities (TRL: production stage) such as digital life storybook may have better outcome than when these interventions and activities are delivered in more traditional way. There is some

- evidence of better mood and engagement and reduced distressed behaviours, although quality of evidence is low.
- A related group is computer-based/electronic technologies in general (i.e., not limiting to touchscreen technology) for engagement (TRL: validation stage). These include activities delivered through different platforms such as music playlists. Although there is some suggestion of positive outcomes in higher human and psychological needs, evidence varies.
- Modest evidence suggests ICT-based social health and participation (TRL: production stage) may be effective in connecting family members with care home residents.
- Virtual reality (TRL: ideas stage) design that involves people living with dementia and carers showed some potential positive outcomes with qualitative evidence.
- Quality of evidence is uncertain for robotics for supporting engagement (TRL: prototype stage), with some suggestions of effects on loneliness, depression, quality of life, reduced agitation and increased interaction and engagement.
- Despite the potential to reduce staff burden and improve engagement with chatbots and socially assistive robots (TRL: ideas stage), evidence on effectiveness is lacking.

#### C. Technologies used on people living with dementia

- There is some emerging evidence that digital biomarkers (TRL: ideas stage) may facilitate early identification. There is no evidence in real-world settings yet.
- Digital cognitive tests (TRL: validation stage) may have comparable performance to traditional paper-and-pencil tests, although validation data are lacking.
- Activity sensors (wearable, non-wearable, and smart home devices; TRL: prototype stage) have very limited evidence. There are some suggestions of correlation with apathy, agitation, etc., but the validity of their use for early detection has been questioned.
- Location tracking systems (TRL: protocol stage) has some evidence of benefits such as safety and carers' peace of mind. More evidence is needed, and usability and ethical concerns need to be addressed.

#### Findings on cost and cost-effectiveness

We found very little economics evidence, although (from published protocols) there are clearly a few RCTs underway with well-designed cost-effectiveness components.

The general paucity of economics evidence is partly because some studies are focused on technologies that are still at an early stage in terms of readiness, and so the evaluations are looking at prototypes or small pilots. However, even when full effectiveness evaluations have been conducted in real-world settings, it is surprising that so few include an economics component.

A further complication in looking at the economics evidence is that most digital technologies are developed in the commercial sector and marketed to public and private purchasers. The cost to the health and social care systems (whether public or private), therefore, is the market price plus whatever staff and other resources need

to be deployed to initiate and support implementation. Market prices can go up or down, and so too could the cost of the associated resources.

#### The economic evidence

- There is some old evidence (from 1998) from a public agency perspectivebased evaluation that, with a computer system designed to reduce carer social isolation and increase their confidence in decision-making, the cost has increased but led to better carer confidence. However, it cannot be said whether it was cost-effective.
- The video-initiated intervention FamTechCare was more expensive than telephone support, but also generated better improvements in depression and competence. The improvement in carer mental health is, however, likely to have led to a reduction in carer utilisation of healthcare. It consequently underestimates the economic case for this intervention.
- An exploratory study of homecare assistive devices and safety technologies in Finland showed that patients with Alzheimer's disease were able to stay longer in their own home before going into residential or nursing home care, suggesting reduced costs. However, there was no control group, and so no conclusion can be drawn.
- Compared with an internet-based video conferencing support group, an internet-based chat support group is more effective in improving the mental health of carers of people living with dementia. Costs of professional time allocated to supporting video conferencing did not differ from costs for clinicbased services.
- The Telehealth Education Program (TEP) provides education and support for spouse carers of people with moderate-to-severe dementia. Comparing healthcare service use and costs with usual care, TEP produced cost savings of nearly USD3,000 per person over a 6-month period, which may be due to delayed admission. However, several key limitations with the study should be noted, such as a lack of outcome data and costs for the intervention itself.
- The NIHR-funded ATILLA trial did not find better outcomes with an individualised ATT device compared to smoke and carbon monoxide detectors and a pendant alarm. Over 24 months, there was no evidence of costeffectiveness.

#### Barriers to scaling up technology

Drawing on our previous study, our new literature review, and our discussions with a few researchers, we highlight here the main barriers:

- Evidence barriers
- Price barriers
- Design barriers
- Trust barriers and preferences
- Awareness barriers
- Individualisation barriers
- Commissioning barriers
- Societal attitudinal barriers
- Staff skills, awareness and attitude barriers

These barriers are not new, nor unique to dementia care. It is the norm rather than the exception that technologies in health and social care, many of which appear promising, face challenges of non-adoption, abandonment, difficulties in scaling up, spread, and sustainability (the NASSS framework).

#### **Conclusions**

To address the above repeating story of slow progress in developing digital technology to support people living with dementia and carers, policy direction and strategies should be in place, using NASSS as a framework in prioritising research funding support in digital technology, on top of existing health technology assessment (HTA) criteria of effectiveness and cost-effectiveness of interventions.

Considering the potential evidence on effectiveness, cost-effectiveness, readiness and scalability, digital technologies that appear relatively more promising include mobile, touchscreen, ICT, and multimedia to support daily functioning, meaningful activities, social engagement, and virtual care that involves tailored dementia-care strategies delivered with a co-resident carer. These technologies have two common features:

- deploying/repurposing existing commercial solutions for people living with mild to moderate dementia; and
- in line with current theory and evidence, they emphasise person-centredness, social connectedness and meaningful engagement.

These features lead us to recommend positioning digital technologies in a supportive/enhancing role in the overall development of non-pharmacological care and interventions for people living with dementia, rather than being a standalone strategy.

The main cost drivers in dementia care are family and social care (rather than medical care). Digital technologies that will have better potential to be effective and cost-effective are those that directly target higher-level, human and psychological needs to preserve personhood, quality of life and wellbeing of the person living with dementia and their carers. The *form* of digital technology, when taken out of its care philosophy and application context, is a less relevant aspect of consideration in prioritising resources.



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Please contact the NIHR Older People and Frailty PRU for assistance.

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The full report with references is available here.

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