Engineering and Physical Sciences Research Council (EPSRC) and National Institute for Health & Care Research (NIHR) workshop: ‘What are the opportunities for engineering and physical sciences research in dementia?’

On Tuesday 20th June 2023, NIHR and EPSRC hosted a virtual workshop which sought to identify opportunities for engineering and physical sciences research in dementia, including across a range of themes and identifying where progress has already been made. The workshop was not an exercise to prioritise specific research topics for Government funding, rather it sought feedback from attendees on what funders can do to support the use of engineering and physical sciences research to address issues identified in previous prioritisation exercises such as the Alzheimer’s Society dementia research roadmap. The workshop was chaired by Professor of Biomedical Engineering, Christopher James from the University of Warwick.

The workshop brought together a range of academic experts, people living with dementia, charities and organisations and attendees contributed a wealth of perspectives.

1. Opening address: Understanding the lived experience of dementia

Richard Oakley, Associate Director of Research and Innovation at Alzheimer’s Society and Michael Booth, a former carer and now a person living with Young Onset Alzheimer’s opened the workshop by setting out the current challenges and opportunities in dementia research, including what is important to people with lived experience of the disease.

They identified the dementia diagnosis process as being too memory-focused, the lack of support and stigma which surrounds diagnosis and the need for earlier and more accurate diagnosis of dementia. The NHS currently lacks the infrastructure required to provide specific diagnosis of dementia and to support the prescription of treatments.

They highlighted how 80% of people living with dementia are living at home rather than in a care home and there is a need to support people to live at home independently and for longer. Mobility and communication aids and technologies to support independence are important but many are old fashioned and not fit for purpose. Memory loss is not the only symptom of dementia, other symptoms such as tremors and a loss of mobility should be taken into account as part of research exploring the management of symptoms.

2. Panel session: How can we improve the lives of those impacted by dementia through physical sciences and engineering research?

Four panel members shared their thoughts on how we can improve the lives of those impacted by dementia through physical sciences and engineering research. The panel included John Terry, Katie Brittain, Michael Booth and Simon Lord. They emphasised the importance of involving a variety of different people with lived experience of dementia in research, acknowledging that not everyone with dementia is elderly. Those living with dementia have different needs based on their age and disease type and research should support them to live independently beyond the home, in neighbourhoods and communities. Research and technological solutions should also reach those most in need, acknowledging that experiences of dementia are unequal, and inequalities exist in dementia diagnosis, care and support. Technologies should be used to help relieve the burden of dementia and not contribute to it; it is important that we consider how to improve the quality of life for those impacted by the disease.

The panel emphasised the importance of creating multidisciplinary research teams to address challenges in dementia and develop technologies and solutions that promote independence and personalise care. The importance of research translation was raised as an area which funders should be supporting.
Panel members were asked what good looks like for dementia health care and support which we should be aspiring to achieve, and responses included: providing independence and good quality of life, fast diagnosis and treatment, personalised care and treatment and a cure for dementia.

3. Break out session: Exploring opportunities and challenges in dementia for engineering and physical sciences

Attendees took part in break out room discussions across a range of themes and were asked to identify priority areas for research.

Living well with dementia

Care for people with dementia is equally as important as diagnosis and treatment. Systems and tools developed by research to support people to live well should be designed to address people’s needs, not be over-complicated and should not shift the burden onto carers or the person using the technology. Research should not be overly focussed on ‘novelty’, dementia research can still benefit from the implementation of current technologies to enable people to live well. This should particularly be the case where technologies have been successfully mass produced at a low cost and their benefits can be extended to also support people with dementia.

Technologies and solutions should be implemented to enable people with dementia to live independently in a way which does not make them feel abandoned.

End of life care

End of life care was recognised as a difficult research area due to the uncertainty of disease progression. Technologies and solutions should be developed to improve life expectancy whilst also maintaining quality of life as much as possible. Although there is a need for protocols to be developed to enable effective access and use of technologies and solutions by health and care professionals. There are lots of exciting new technologies emerging which will support people with dementia who are receiving end of life care, however, we must better use current technologies to support those who are in need right now. Use of technologies and solutions can help people stay and die comfortably in their own homes.

Music therapy can support end of life and improve quality of life for people with dementia. Wearable non-invasive devices can measure brain activity to understand where mood or stimulation may require improvement and music can be initiated at this point to reduce agitation and provide cognitive stimulation.

Detection and diagnosis

Identifying and understanding those at risk of dementia (e.g. using data and AI) would enable the triage of patients for further diagnostic tests which could lead to an earlier diagnosis. This could also be supported by using digital biomarkers. MRI scanning could be improved via engineering and physical sciences research to improve the timeliness and specificity of dementia diagnosis. Tools could be developed to detect and predict the symptoms of patients, such as the early detection of amyloid-related imaging anomalies. There is a view that a lot of work is needed to optimise the patient trajectory through diagnosis and the patient pathway.

Disease and progression-altering interventions

Discussions centred around technologies or solutions which can be developed to enable disease and progression-altering interventions for people with dementia. Interventions could include biosensors to detect risk of falls or dehydration and therefore prevent avoidable health problems that can lead to hospitalisation. Diagnostic and screening tools can be developed, particularly at
home testing and screening interventions and also digital technologies to enable continuous health monitoring. Other ideas included the use of decentralised clinical trials and technology-enabled platforms, for example, using smart home infrastructure and remote sensing using radar for observing physiological and behavioural biomarkers.

4. **What can funders do to help?**

Attendees were asked to consider how funders can enable the use of engineering and physical sciences research to solve challenges in dementia. There were a wide range of suggestions, including funders undertaking a mapping exercise to understand what is happening at a macro and structural level to inform how to best deliver health care. This approach is complementary to understanding the lived experience of dementia. The importance of funders promoting and specifying the need for patient and public involvement and engagement was frequently reinforced by attendees, particularly the need to ensure involvement in the application process. It was noted that time is needed to build relationships between researchers from across disciplines to establish multidisciplinary teams and identify shared interests. Funders should provide opportunities for communities to come together, including via funding calls and cross-funder opportunities.

5. **Next steps**

NIHR and EPSRC are reflecting on the valuable ideas and priorities shared during the workshop and will inform potential opportunities for collaboration between funders to use engineering and physical sciences research to address challenges in dementia.