NIHR | Applied Research Collaboration Kent, Surrey and Sussex

Living well with dementia - researcher and stakeholder event

Summary report

March 2023

Introduction

This year's NIHR Applied Research Collaboration Kent Surrey and Sussex's (ARC KSS) annual dementia strategy group meeting was held on 9 March 2023 in Gatwick.

The meeting was split into two sections: an early career research showcase session in the morning, followed by a stakeholder strategy event that focussed in the system priorities now and over the next three to five years, in the afternoon.

The purpose of the research session was to enable the ARC KSS dementia theme early career researchers to showcase their work to each other and key system stakeholders.

The aim of the stakeholder strategy event was to encourage stakeholders, from across Kent, Surrey and Sussex's NHS Integrated Care Boards (ICBs) to share challenges and identify opportunities for the ARC KSS to support services and improve the care for people with dementia by undertaking meaningful research to the system.

This was not standalone event. Instead, it compliments regular, regional and Integrated Care Board (ICB)-based strategic and operational meetings. These regular meetings are, effectively, communities of practice, bringing together people and supporting dementia pathways including: mental health, acute trusts, primary care, ageing well teams, social care, voluntary and community sector organisations, and public representatives. The voice of people living with dementia and their carers are also heard in regional reference groups, through dementia envoys, lived experience panels, and from local and national charity representatives such as: Know Dementia, Alzheimer's and Dementia Support Services', Age UK and The Alzheimer's Society.

We need to demonstrate that the research we fund and support understands and responds to integrated care system priorities, in order to apply research outputs that are recognised and meaningful to the system. The aim of this summary is to highlight the core themes highlighted at our strategy event by stakeholders from across Kent, Surrey and Sussex and seek further alignment with wider insights from other stakeholders, including people accessing care. We will continue to work to ensure we are prioritising and meeting the needs of people delivering and those accessing dementia care.

Professor Naji Tabet

Lead for ARC KSS Living Well with Dementia

Kath Sykes

Implementation Manager Living Well with Dementia

Stakeholder strategy event

The impact of dementia on society and the health and care system:

The number of people with dementia is predicted to rise to 1.1m by 2030, 1.4m by 2040 and will reach 1.6m by 2050

If the onset of dementia was delayed by five years the savings would be £21.2bn a year by 2050 (£38.2bn from £59.4bn)

The economic impact of dementia is similar to cancer, and greater than heart disease and stroke

The majority of dementia costs per year are due to social care, costing £12.5bn (50%) per year. Informal care costs £10.2bn (41%) and healthcare costs £1.7bn (7%). The total cost is almost £25bn

*21 out of 27 people on UHS dementia ward medically fit for discharge

Dementia was the no. 1 cause of death in women, and 2nd cause of death in men in 2019

A few core questions considered by the group

Does the system understand the impact of dementia right now? What can we do to highlight this? Does the system understand the incidence, the cost, the impact, right now, as an example on hospital admissions, cause of death, rates of death, impact on other health and care priorities such as repeat admissions and delayed discharges?

Is dementia lost under mental health including focus by NHS England on diagnosis rates? As an example, mental health services (generally) diagnose and manage challenging behaviour, but other significant care providers include neurology for diagnosis of complex and early onset dementia: Primary care for diagnosis and ongoing care; community health services for day to day health needs and living well; voluntary sector for living well and reducing isolation; social care for safeguarding and supporting people to live at home and in care; end of life care – dying well with dementia. Not forgetting the significant impact of dementia on the individual, their family, and other informal carers. No single care provider has overall responsibility for supporting people living with dementia and this leads to fragmentation of health care, not helped by health and care IT systems not integrating with one another.

The group noted that dementia is not integrated into each system's 'ageing well' workstream – dementia can be seen as purely mental health, although a lot of people with dementia will never need to come under the care of an old age psychiatrist. The Ageing well workstream also has more resource but may not be designing services around cognitive challenges due to considering such challenges as falling under mental health services. Healthy ageing opportunities and the overlaps between physical and cognitive ageing need to align for effective prevention work. Can frailty/ageing and dementia work more closely together?

Risk was noted that the removal of annual reviews for dementia from the Quality Outcome Framework means primary care may be less incentivised to undertake dementia annual reviews, reducing the quality of care provided by general practice. Polypharmacy has also been raised as an ongoing risk.

The group expressed concern about the number of people with dementia presenting in crisis, highlighting that the current focus is reactive, not proactively reducing the risk of crisis occurring in the first place.

Workforce: as above, but particular concerns were raised about the capacity of old age psychiatric teams to review people in crisis- including in acute trusts. Concerns were raised about GP knowledge of dementia, their workload, and sustainability. It was noted that there is a lack of understanding about dementia in wider workforce, resulting in a lack of confidence in treatment/support of people living with dementia (PLWD) and, therefore, a lack of consistency of care.

The group recognised there is a lack of public awareness of dementia, a need to reduce stigma in communities and, therefore, reduce delays in diagnosis.

Throughout the group the point was raised that there is also a risk that diagnosis is not accurate due to a lack of access to the most suitable/relevant diagnostic techniques, and lack of application of appropriate tests. This then has an impact on access to appropriate care and support for PLWD. There was a specific request to develop a framework for diagnosis including imaging, bio markers etc. by the group.

The group asked whether we could do better optimising delirium prevention and management. For example, establishing what are best models, including dementia assessment after delirium presentation. Delirium is often the reason old age psychiatrists need to be involved in acute care. It's a common presentation in older adults which causes individual morbidity and has significant care resource implications.

Prevention and mild cognitive impairment pathways need more development and to be applied consistently across the health and care system, including ageing well.

We need better understanding of differences in risk and safeguarding between health and social care. As an example, are there differences in mental capacity assessment and tolerance with fluctuating capacity? For example, could this be due to risk of adverse incidents versus concern of deprivation of liberty, and impact-including adequate care provision.

We discussed the challenges of:

- paying for dementia care and impact of paying for care on individuals and families and their decision making.
- providing proactive and quality support to people living alone with dementia.
- supporting informal carers to care for their loved ones living with dementia.

There was an ask from stakeholders that research stops asking the same questions.

Suggestions of how the Living Well with Dementia theme could support regional research priorities

Over the next three years

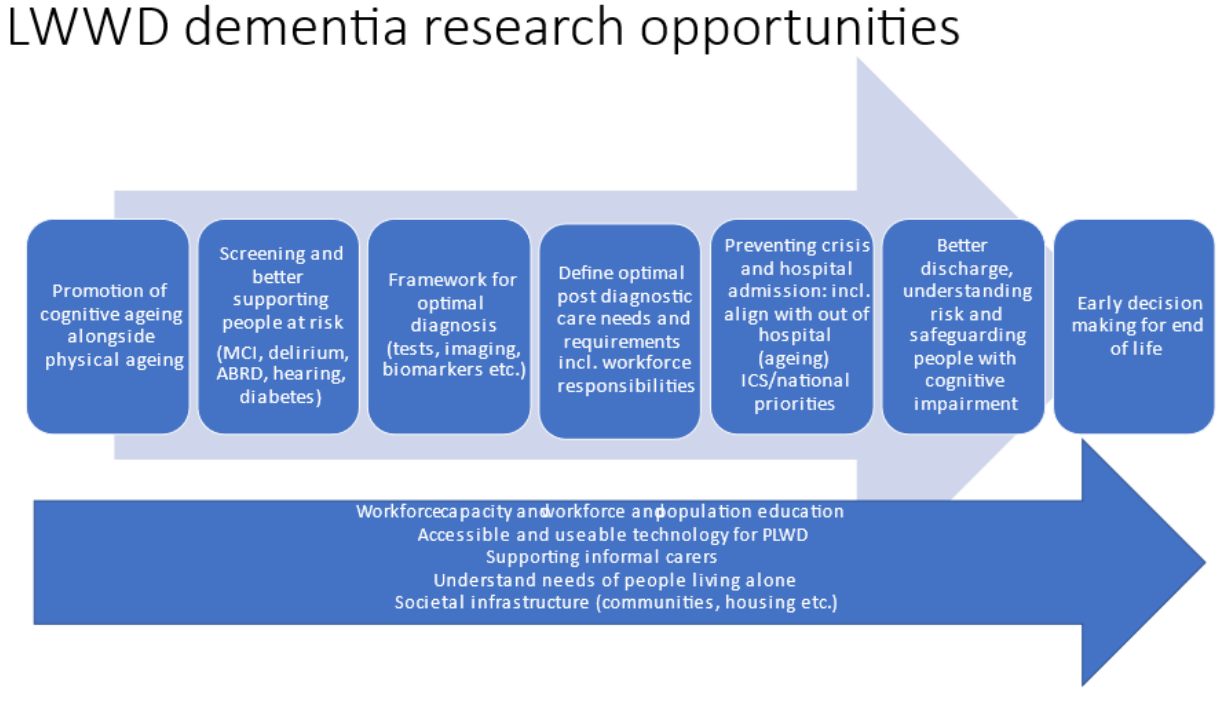
- Develop a framework for optimal dementia diagnosis to standardise diagnosis and access to diagnostics (imaging, biomarkers, improved cognitive tests – including education and cultural sensitivity) across the region and nationally. This will also support access to research and new treatments.
- Develop optimal delirium pathway including prevention.
- Develop optimal Mild Cognitive Impairment (MCI) pathway.
- Explore other opportunities to screen for dementia: using integrated data, at hearing tests/screening.
- Utilising accessible and useable technology designed with people with dementia/MCI to support them to live well, independently and keep them out of acute hospitals.
- Optimising existing supportive technology cross care settings e.g. Alexa in hospitals
- Using technology to support delivery of care e.g. virtual reality (VR), artificial intelligence (AI) and virtual cognitive stimulation therapy.
- Define workforce structure, training needs, and responsibilities needed to provide optimal care for people living with dementia.
- Understand what is needed to develop and support integrated care pathways for dementia.
- What does good look like to people living with dementia and carers? Are we learning from the impact of poor-quality care?
- Building hope and ensuring meaningful support after a dementia diagnosis.
- How do we include people living with dementia in advances and the opportunities provided by out of hospital care. including accessible technology?

Longer term (five year) opportunities (including building on mid-term opportunities)

- Artificial intelligence for diagnosis (imaging, risk, and individualised supportive technology at home).
- Clear road map to optimal care framework for different dementias.
- Understanding impact of dementia communities, optimising housing etc.

Opportunities to work agilely and support local and existing projects (informally or formally)

- Evaluating Communication and Interaction Training (CAIT) training - regionally led by University Hospitals Sussex, funded by Health Education England - and aims to reduce challenging behaviour in acute trusts and care homes.
- Evaluating DIADEM dementia assessment in care homes and domiciliary care- regionally led by Kent and Medway.
- Evaluating local frailty initiatives to use frailty teams to screen for dementia. Kent and Sussex.
- Supporting projects looking to screen diabetic patients for dementia in clinic.
- Determining optimal delirium pathways and dementia diagnosis models- avoiding delays in dementia assessment in Surrey.
- Opportunity to support Integrated Care System (ICS) priorities such as urgent community response and virtual wards to raise profile of dementia and make sure that people living with dementia are not being excluded from services they may benefit from in Kent and Sussex, and Surrey.
- Opportunity to include a HIV population in the 'NoDem' study.



1. Current ARC KSS projects

During the event, we presented a reminder of some of the research we are supporting and or funding, which include:

Ongoing research

- DETERMIND: DETERMINants of Quality of Life (QOL), care and costs and consequences of inequalities in people with Dementia and their carers.
- DREAMS START: (Dementia Related Manual for Sleep; Strategies for Relatives) is a psychological intervention programme feasibility randomised controlled trail (RCT).
- EMBED care: Empowering Better End of Life Dementia Care.
- NODEM: Practices, attitudes, and outcomes for patients with memory complaints but no dementia diagnosis following memory clinic assessments (Brighton and Sussex Medical School).
- Realist evaluation of dementia care coordinators in Kent and Medway (University of Surrey).
- CoCOG: Co-designing a health and well-being assessment digital tool for people diagnosed with mild-to-moderate cognitive impairment (ARC KSS strategic collaboration).

PhD studies

- Determinants of multiple admission to acute hospital wards for older people with Dementia (Brighton and Sussex Medical School).
- Alcohol and Early onset Dementia (University of Kent).
- Assessing the cost-effectiveness of interventions for dementia using a care pathway approach (University of Greenwich).
- Enhancing and Improving End of Life Care (UoC, and UHSW) (non-beneficial care at end of life care, including dementia)
- Dementia – decision making at discharge (UoC and UHSW)

Individual Development Awards

- Technology Integrated Health Management (TIHM) and delirium

Implementation Study

- My Choice: developing an accessible evidence-based resource to support people living with dementia.
- Completed studies
- Remote Memory Assessment Service (RMAS).
- The impact of COVID 19 on people living with dementia.
- Technology Integrated Health Management (TIHM) monitoring service.