

ARC KSS Living Well with Dementia – MONTHLY ROUNDUP

THEME HIGHLIGHTS

Welcome to the second [ARC KSS Living well with Dementia](#) round up. We hope you find this helpful, and welcome your feedback to ensure this meets the needs of you, our collaborators.

This month we are pleased to introduce our new Post Doctorate [Rebecca Atkinson](#) to the team.

If you haven't already please do: [Join Dementia Research](#), and register your interest in taking part in vital dementia research, and encourage others to do so to.

Our main focus as we approach summer is the opportunity through the NIHR Dementia Highlight notice. We are aiming to engage with people accessing services and those delivering services to support submission of a number of applications from across Kent Surrey and Sussex.

We have added a new section in this roundup with a spotlight on important studies recruiting in KSS.

UPCOMING EVENTS

June

[Ageing Well: How can we turn the problem of ageing into the most promising opportunity of the 21st century?](#)

[ARC KSS Annual Dementia Research event \(2 sessions\)](#)

FUNDING CALLS

[NIHR various Dementia funding opportunities](#)

[AHSN funding newsletter](#)



Dr Naji Tabet

Theme Lead for Ageing Well:
Living Well with Dementia



Kath Sykes

Implementation Manager for
Ageing Well: Living Well with
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Updates across the Theme:

DEMENTIA GENERAL UPDATE:

Please do join us for our Annual ARC KSS Dementia Research event on 30th June 2021. This is separated into 2 sessions- the morning will focus on research activity to date, and the afternoon session will be a community of practice to help establish our research focus over the next year (tickets available [here](#)).

The NIHR has released a [Dementia Highlight notice](#) for prioritised funding for Dementia in various research programmes. There is particular focus on recruiting from areas where there is a mismatch between the incidence of dementia and research for dementia, and also to address equality, diversity and inclusion. We aim to take full advantage of this opportunity and will work collaboratively across KSS to submit high quality applications that represent our population. If you have any research ideas please do get in contact with us.

CRIS

The Clinical Record Interactive Search program [CRIS](#) has been adopted in both Kent and Sussex Mental Health Trusts, with the aim of adoption and standardisation of dementia datasets across Kent Surrey and Sussex. CRIS will provide structured and [Natural Language Processing](#) (NLP) derived data on dementia diagnosis, and will capture the various symptoms and symptom clusters (e.g. agitation, aggression, depression symptoms) as well as medications. Once the first data load onto CRIS has completed we will work with relevant teams to identify any gaps in data, and standardise this across Kent and Sussex.

MEMORY ASSESSMENT:

[Dr Gosia Raczek](#) has now recruited 73 people to her remote memory assessment study exploring patient and clinician satisfaction and clinical outcomes. Gosia has also secured funding to help develop a tool kit for commissioners and services wanting to provide remote memory assessments, and information for patients and carers on what to expect and how to prepare for virtual consultations.

The Alzheimer's Society is conducting research into the provision of remote appointments within memory services during the pandemic to look at the challenges and opportunities of delivering these types of appointments for people living with dementia. The survey responses will inform and feed into a larger project around improving access to a diagnosis. They are looking for responses from clinicians working with memory services. <https://www.smartsurvey.co.uk/s/O76SZQ/>

Please also details of **ADePT** – Accelerating Dementia Pathway Technologies, and SPFT study in the other research news section below.



MANAGING TRANSITIONS AND CARE WELL (Incl. EOLC):

The Dementia Researcher service has organised a special webinar hosted by [Dr Emily Oliver, Lead Dementia Nurse for Portsmouth Hospitals NHS Trust](#).

Aimed at all healthcare professionals this webinar will feature a number of researchers whose work is focussed on improving the care that people living with dementia receive whilst visiting or staying in an NHS hospital..

21st May 13.30 - 15.00 BST

Subjects include:

'When people living with dementia say 'no': Negotiating refusal in the acute hospital setting'; 'The role of the NIHR Centre for Engagement and Dissemination, in supporting NHS services'; 'Involving families in the general hospital care of people living with dementia: how well are we doing?'; 'Exercise and Dementia and interventions on a chair-based exercise', and 'Improving frailty care pathways'

Register via Zoom - https://ucl.zoom.us/webinar/register/7116208443441/WN_3rK6kX7zTy-5yMTQK9W9-Q

If you cannot attend live, watch back via YouTube - <https://www.youtube.com/channel/UCe1qv0E1UzNPtGhz2nQaoig>

EXPLOITING THE POTENTIAL OF ASSISTIVE TECHNOLOGY:

Why do people abandon assistive technologies? Research suggests users need to be partners in design

The findings in [this NIHR study](#) suggest that the design and provision of assistive technologies must change. The researchers suggest that users must be more involved in the design process. A shift in emphasis is needed from the clinician being the expert, to more patient-specific solutions with designs and decisions based on each person's needs. Change at the level of government, industry and commissioners will be required to achieve this, but also among clinicians and the users themselves.

COVID-19:

The Time for Dementia and DETERMIND research teams are pulling together the results of their two COVID Quality of Life studies to summarise findings to support service providers and commissioners in delivering care to people with Dementia and their carers post COVID. We will share this once completed.



STUDY SPOTLIGHT: DETERMIND

DETERMIND is an ambitious study which aims to find out which groups have better or worse outcomes following diagnosis of dementia and why there are inequalities in care and outcomes

Although we know it is possible to live well with dementia, there are people who will experience great challenges post-diagnosis and these are likely to negatively impact on their quality of life. DETERMIND aims to explore and address the inequalities in the post-diagnostic care pathway so that in future everyone can have equal access to care services and the greatest opportunity to live well with dementia.

To achieve this, the study team will speak to newly diagnosed (within the past 6 months) people with dementia and their care partners on a yearly basis for the next three years. The research team will visit participants to discuss their experiences of accessing services and funding as well as their thoughts on their mental, physical and social well-being. This study provides a great opportunity for people to express their opinions and feelings about dementia as well as help us to improve the care pathway for future generations who will be diagnosed with the condition.

This study welcomes anyone with a recent clinical diagnosis of dementia. They are particularly keen to hear from people who identify as LGBTQ+ and those from black, Asian and minority ethnic groups as we know that these populations can be at particular risk of poor care outcomes following a diagnosis of dementia.

Inclusion criteria

Persons diagnosed with any type of dementia within the past 6 months and their carer, either formal or informal.

If you would like to get in touch then please contact Dr Ben Hicks on b.hicks@bsms.ac.uk and for any further information on the study please see the study website: [DETERMIND](#)



Dementia PhD's Updates and training opportunities

"Determinants of multiple admission to acute hospital wards for older people with Dementia" [Megan Zelenka \(BSMS\)](#)

"Practices, attitudes, and outcomes for patients with memory complaints but no dementia diagnosis following memory clinic assessments" [Sana Bestwn \(BSMS\)](#)

"Alcohol and Early onset Dementia" [Vijay Delaffon \(UoK\)](#)

We are really pleased to welcome new PhD students working on the following studies:

"Enhancing and Improving End of Life Care" (UoCh, and UHS NHS Trust) (*non beneficial care at EOLC incl. dementia*) Ross Webster

"Dementia & Decision Making - Supporting Transition in Acute Care Settings" (UoC, and UHS NHS Trust) Camille Cousley

"Assessing the cost-effectiveness of interventions for dementia using a care pathway approach" (UoGreenwich)

ARC KSS Training opportunities

For more details on how ARC KSS is supporting early career researchers including training, mentorship, and funding opportunities please see the Academy/Learning and Development section of the ARC KSS website [here](#). Please also sign up for the [ARC KSS Academy Newsletter](#) to hear of regional training opportunities for early career researchers.

Sharing Dementia Research Events / Jobs / Education Courses / Research Funding Calls

[The NIHR Dementia Researcher service](#), supported by Alzheimer's Society and Alzheimer's Research UK also provides a range of support and resources for dementia researchers, particularly those working at the early career stage.

As part of the service they collate and share listings of dementia specific research funding opportunities, events, jobs and higher education courses. The team behind the website wish to highlight that CHAIN Members can directly add to these listings using their websites self-service function.

ARC KSS is recruiting to a Darzi fellowship in Clinical Leadership

This has a focus on supporting services to support and utilise research, and developing the successful individual in clinical leadership. Please see more details here:

<https://arc-kss.nihr.ac.uk/news/darzi-fellowship-in-clinical-leadership-opportunity> - closing date 31st May 2021.

Other Research News and Useful Documents:



Dementia Action Week 2021 – Alzheimer's Society

Dementia Action Week 2021's campaign focuses on social care reform, at a crucial point in Government development of social care planning.

Right now, nearly 1 million people with dementia and their families are struggling to get the support and care that they need and deserve. Decades of underfunding and neglect have led to a care system that's difficult to access, costly, inadequate and deeply unfair. The coronavirus pandemic has exposed these problems like never before.

For Dementia Action Week 2021 Alzheimer's Society is calling on governments to cure the care system now. To provide quality social care, that is free and easy to access, no matter where you live. Because while dementia isn't curable yet, the care system is.

There are lots of ways to get involved in Dementia Action Week:

- The Alzheimer's Society are asking everyone to [sign and share the petition](#), our petition to Prime Minister Boris Johnson and the First Ministers of Northern Ireland and Wales to reform social care once and for all.
- Share our powerful film for the Week on social media and with your networks (from 11 May) [Dementia Action Week | Alzheimer's Society \(alzheimers.org.uk\)](#)
- Follow us on social media and share our Dementia Action Week post
- [Order your Dementia Action Week printed materials](#), that include free posters and flyers and display them in your community (from 20 April)
- [Share your story](#) to show Government the impact the broken social care system has on everyday lives across the UK.

To stay up to date with our plans for the week and to order materials, please visit [alzheimers.org.uk/DAW](https://www.alzheimers.org.uk/DAW)



ADePT – Accelerating Dementia Pathway Technologies

Early identification and diagnosis of Dementia is essential for improved health outcomes and service provision. Sussex Partnership NHS Foundation Trust are running a trial to explore a new and innovative cognitive assessment tool from Cognetivity Neurosciences- the **Integrated Cognitive Assessment (ICA)**. This is a five-minute computerised test which is a quick and easy test of cognitive performance- using an iPad.

Once consented through memory assessment services patients will take the ICA, as well as all of the other standard assessments taken as part of their appointment. The aim of this study is to build clinical and cost evidence and see whether the ICA could be an inexpensive dementia screening tool for the NHS.

Anyone 55 to 90 years old who have been referred to a (Sussex based) memory clinic by a general practitioner is eligible to take part in this study.

If you are interested in finding out more about ADePT or about the research we are involved in, please get in touch via email at dementiaresearchunit@sussexpartnership.nhs.uk or phone on 01892 603107 (please leave a message).

Or visit our website: <https://www.sussexpartnership.nhs.uk/our-mental-health-research>

NICE have opened the consultation on indicators for antidepressant prescribing and dementia: <https://www.nice.org.uk/standards-and-indicators/consultation-on-indicators-for-antidepressant-prescribing-and-dementia>

Comments are invited on the proposals for general practice indicators on:

- Reviews for patients prescribed a new course of antidepressant medication or in receipt of long term antidepressant medication.
- Care planning and medication reviews for people with dementia.

Further information and the comments form are available via the link above.

The consultation will be open until **5pm on 25 May 2021**. Please share with any stakeholders who may be interested.

That Co-production Podcast!

The Research Design Service South East (RDS SE), in partnership with the National Institute for Health Research (NIHR) Centre for Engagement and Dissemination, have launched a podcast series: ['That Co-production Podcast!'](#) . These are also available on soundcloud and spotify: [NIHR RDS SE](#)



The **ENRICH** care home network brings together care home staff, residents and their families with researchers. It provides a toolkit of resources to help care homes make the most of research; and researchers to set up and run studies effectively and collaboratively in care homes. [ENRICH \(nihr.ac.uk\)](https://www.nihr.ac.uk)

If you haven't already please do [Join Dementia Research](#), and register your interest in taking part in vital dementia research, and encourage others to do so t.

If you are interested in joining the ARC KSS Dementia Team as a public advisor please contact Pippa Shaw, ARC KSS PCIE lead, for more details: <https://arc-kss.nihr.ac.uk/public-and-community-involvement>

For further information about ARC KSS please contact us at: <https://arc-kss.nihr.ac.uk/contact>