

ARC KSS Living Well with Dementia – MONTHLY ROUNDUP

THEME HIGHLIGHTS

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

Our first round up aims to provide an update on our progress over our first year, future plans and engagement, research and collaboration opportunities, as well as provide a summary of documents from networks across KSS and nationally.

Over the last year we have:

- Funded two COVID related studies and supported other Dementia studies.

- Recruited to our main theme infrastructure, including our Post Doc who will start in May.
- Started to recruit to theme PhDs.
- Engaged with the system to understand need and start to align priorities.
- Held two virtual events, started theme related communities of practice, and actively engaged with PCIE.
- Supported a number of research applications.

Welcomed our first theme [public advisor](#), Karin Webb



Dr Naji Tabet

Theme Lead for Ageing Well:
Living Well with Dementia



Kath Sykes

Implementation Lead for Ageing
Well: Living Well with Dementia

UPCOMING EVENTS

April

[Ageing Well: Can Disruptive Innovation help people to age better](#)

[Revisiting and Reflecting on the Role of PPI in research Impact on Individuals, Research and Organisation](#)

[Getting involved in Dementia Research- How and Why?](#)

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](#)



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 (ticket link above).

The NIHR has released a Dementia Highlight notice (see link above) for prioritised funding for Dementia in various research programmes. We aim to take to advantage of this opportunity and will work collaboratively across KSS to submit high quality applications that will ultimately benefit our population.

The ARC KSS Dementia team held their first ARC KSS Dementia Strategy Group in January, which will support the strategic development of the Ageing Well Living Well with Dementia ARC KSS theme, and associated researchers across Kent, Surrey and Sussex. This strategy group will be held quarterly and will feed into ARC KSS governance, other regional research meetings and facilitate research opportunities and collaborations across KSS.

Dr Naji Tabet and Kath Sykes are now established members of system level Strategic Dementia Groups across Kent, Surrey and Sussex. This enables us to understand regional needs and priorities and help lever opportunities for collaboration, it is also a great way to share the findings from our research projects in a timely way, and promote what we are doing in the ARC.

MEMORY ASSESSMENT:

We are eagerly awaiting the results from the ARC KSS funded remote memory assessment study led by [Dr Gosia Raczek](#). Gosia is exploring patient and clinician satisfaction and clinical outcomes, and has been able to share that the findings to date show video assessments are acceptable to the majority of patients. The moment full findings are available we will share them with you.

Also see update from Sana Betswn our PhD student exploring outcomes for people with a diagnosis of MCI following memory assessment in PhD section below.

AGEING WELL, COGNITION, FRAILITY, AND MULTIMORBIDITIES:

The first Ageing well: Changing the conversation Community of Practice was held by the University of Sussex on 23rd February. This is a community of people and organisations interested in discussing, debating and disrupting how we age well. It's a place to share ideas, build collaboration and move towards changing the conversation around how we age, and we look forward to working with this community. If you are interested in joining this community please see details of upcoming events above.

This community is funded by the University of Sussex and the ESRC to help translate academic knowledge into action. Please contact Nora Davies, project manager of the ESRC Impact Acceleration Account to join this community: n.davies@sussex.ac.uk

We have also started engaging with the HIV team at BSUH to explore how we can support research that supports HIV and cognition. This was a key area in the ARC KSS application to the NIHR, and great to be working with this team.



MANAGING TRANSITIONS AND CARE WELL (Incl. EOLC):

We are continuing to work closely with a Kent Surrey Sussex wide collaboration of End of Life Care clinicians and academics to explore research opportunities that will benefit our population. Our theme focus is on Dying well with Dementia, and there are also emerging discussions with [Professor Heather Gage](#), Theme Lead for our [Health and Social Care Economics](#) theme about access to services including Hospices.

We are looking forward to welcome three more PhDs supported through member organizations commitment to ARC KSS. These will be focusing on:

- Assessing the cost-effectiveness of interventions for dementia using a care pathway approach, University of Greenwich
- Enhancing and Improving End of Life Care, University of Chichester and Western Sussex Hospitals NHS Trust

EXPLOITING THE POTENTIAL OF ASSISTIVE TECHNOLOGY:

This year we will be working very closely with the ARC KSS [Digital theme](#) and with Theme Lead Dr Jo Armes and post doc [Dr Nyangi Gitamwi](#) are planning two approaches to develop our assistive technology sub theme:

1. A [Sandpit](#) type event to explore opportunities for supporting screening of cognitive difficulties.
2. A community of practice planned for the 30th June, to establish needs, gaps, opportunities in relation to assistive technology from people living with dementia and their families, and those delivering care.

We are also delighted that [Dr Josie Jenkinson](#) from Surrey and Borders Partnership NHS Trust will be undertaking an ARC KSS supported research project looking at using assistive technology [TIHM](#) to support people with Delirium in their homes and prevent unnecessary hospital admission.

COVID-19:

In addition to the Remote Memory Assessment study ARC KSS was able to fund another COVID project exploring the impact of lockdown on the Quality of Life of People living with Dementia and their carers. This was led by [Dr Stephanie Daley](#), who recruited participants already enrolled in her [Time for Dementia](#) study. You can see more details of interim findings [here](#), and a video of Steph and people with lived experience of caring during COVID discussing interim findings [here](#).

We are planning to publish the final findings from this study through the ARC KSS website, including the involvement of the Sussex Partnership Foundation Trust Lived experience advisory panel during April.

We will also be combining the results from this study with another study exploring quality of life during COVID- a sub study of [DETERMIND](#), led by [Dr Ben Hicks](#) to develop a document that summarises findings to support the system in developing their carer strategies and support people living with Dementia during and after COVID. We also hope to produce a video telling the impact of COVID on this group later in the year.

We are exploring how we may be able support researchers interested in long (cognitive) covid.



PhD Progress:

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

Megan has made a great start to this study, which was presented at the Centre for Dementia Studies, BSMS event in February. A focused community of practice was held with clinicians and stakeholders across Kent, Surrey and Sussex to support development of the study in readiness for ethics submission. This study will be on temporary hold for 6 months, and we look forward to progressing with this PhD further in September.

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

Sana has also made a great start to this study, which was presented at the Centre for Dementia Studies, BSMS event in February. A focused community of practice was held with clinicians and stakeholders across Kent, Surrey and Sussex, and the Sussex Partnership Lived Experience Advisory Panel have been involved in the development of this study, including feeding back on questionnaires and interview plans. Sana has secured interest in this study from multiple sites across England and she is working hard to submit this to the University of Sussex for Sponsorship and for ethical approval.

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

We are really pleased to welcome Vijay to our PhD team. Vijay is a clinician so has been busy responding to COVID, and will be doing his PhD part time. Initially Vijay will be undertaking an evidence synthesis and we look forward to holding a community of practice, and public engagement work for this study later this year.

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.

Please also see details of a Frailty and EOLC PhD opportunity below.

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 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.



Other Research News and Useful Documents:

FUNDED PHD STUDENTSHIP AT THE UNIVERSITY OF SURREY (deadline 21st April)

Title: Developing Patient Reported Outcome Measures to assist services to meet the priorities of older people with severe frailty at end of life ; using mixed methods - The PRO-Frail study

Summary: Older people with severe frailty will be the main users of palliative care in the coming decades-how their experience at end of life is currently poor; this PHD will review and collect evidence to develop /adapt a Patient reported Outcome measure for elders with severe frailty.

Webpage: Further details about the studentship and how to apply can be found here:

<https://www.surrey.ac.uk/fees-and-funding/studentships/developing-patient-reported-outcome-measures-assist-services-meet-priorities-older-people-severe>

INVITATION TO CARE ASSISTANTS AND NURSES WORKING IN CARE HOMES TO COMPLETE THE ANTIPSYCHOTICS IN DEMENTIA ATTITUDE QUESTIONNAIRE (ADAQ)

Are you a care assistant or a nurse working in a residential or nursing home for elderly residents? If so, please can you help us by completing this questionnaire to tell us your own views about using antipsychotics in residents with dementia? You can save the survey part way through and it should take less than 15 minutes to complete all the questions. Once you have completed the survey, could you please pass on the survey link to other relevant staff who might also be interested in helping us? This survey is part of research being completed by Miss Amna Raza for a PhD in Pharmacy at the University of Reading.

<https://reading.onlinesurveys.ac.uk/adaq-questionnaire-version-3-copy>

The project is being supervised by Mrs Sundus Jawad, Mr Tim Langran, and Professor Parastou Donyai. A collaboration between the University of Reading and NHS East Berkshire CCG

NIHR: VIRTUAL QUIZZES INVOLVING SEVERAL CARE HOMES ARE FEASIBLE AND MIGHT REDUCE LONELINESS AND SOCIAL ISOLATION

Simple low-cost video technology allowed residents in different care homes to enjoy taking part in virtual quizzes. Staff support was needed but new research found that the sessions were feasible and low-cost.

This is the first study to trial connecting care homes virtually via quiz sessions. Interviews revealed that residents felt more connected with each other, and with other care homes. They re-gained a sense of self and purpose and felt less lonely. Care home staff were eager to continue with the sessions, but they outlined barriers such as lack of staff support or time.

Unlike previous research into virtual socialising, this study included residents with dementia. It found that they benefited and remembered faces and conversations.

Read more at: <https://evidence.nihr.ac.uk/alert/virtual-quizzes-involving-several-care-homes-are-feasible-and-might-reduce-loneliness-and-social-isolation/?source=chainmail>



DEMENTIA AND OPMH: GUIDANCE FOR PRIMARY CARE NETWORKS AND CARE HOMES

A [new guidance document](#) has been published on the South East Clinical Network website on the topic of *Dementia and OPMH: Guidance for Primary Care Networks and Care Homes*. This document aims to equip members of staff working in care homes and primary care with understanding of dementia and mental health conditions due to the prevalence of both disorders in care home populations.

MUSIC FOR DEMENTIA LINK WORKER GUIDES

Music for Dementia have just published two guides for link workers, supported by the National Academy for Social Prescribing:

- Full guide: <https://musicfordementia.org.uk/wp-content/uploads/2021/02/Link-Workers-Full-Guide--musical-social-prescriptions-for-people-living-with-dementia.pdf>
- Short guide: <https://musicfordementia.org.uk/wp-content/uploads/2021/02/Link-Workers-1-page-short-guide-musical-social-prescriptions-for-people-with-dementia.pdf>

The guides cover how link workers can include music when supporting people living with dementia, as well as their carers and family members.

PUBLIC AND COMMUNITY INVOLVEMENT AND ENGAGEMENT

The Dementia Consultation Group at Sussex Partnership gave a wonderful presentation about their work at the BSMS Centre for Dementia Studies Research Seminar in February. The group is led by Julia Fountain and works with researchers and share experiences of dementia to inform and guide research. You can see a film of this presentation here: <https://youtu.be/Ze8v4bxdWNY>

Chris Maddox, a member of the group, gave a clear message to researchers: “See the person, don’t see the person with dementia ...Ask us early – get our opinion before decisions are made. Use less jargon and use less acronyms. Remember words are important – being called a dementia sufferer can be hurtful. Think about the timing and length of meeting – we can’t concentrate for long periods of time, allow us short breaks, we can get tired. Please ask us a question and give us time to process and answer, don’t ask us lots of questions at once. Make sure we’ve understood. If there’s a silence, don’t try to fill it, we may still be trying to process and give you an answer. People might hear what we’re saying but might not be listening. Consider the emotional impact research has on us, talking about certain issues may be distressing for us. If you make the meeting work for someone with dementia, it will work for everyone.”

If you want to learn more about patient involvement in research, join the online Approaches to Involvement and Recovery Conference (details in upcoming events section above)

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>