NIHR | National Institute for Health and Care Research

March 2026

Supporting the future generation of Chief Investigators in Applied Dementia Research

NIHR Dementia Fellowships with support from the Alzheimer’s Society [DEM-COMM]

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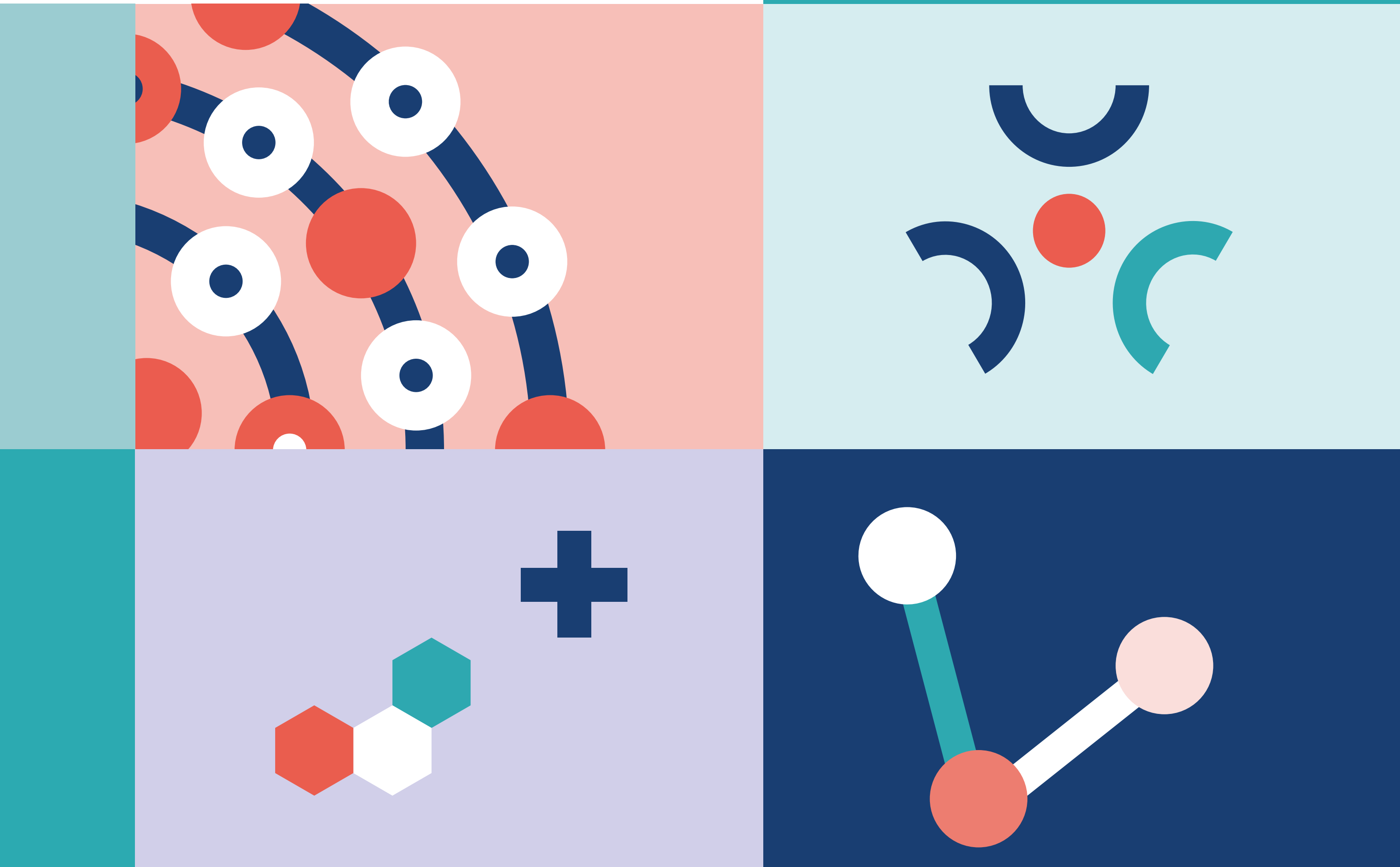


Forewords

Professor Marian Knight
Scientific Director for NIHR Infrastructure

Dementia is one of the most significant health and social care challenges we face. Working out how to prevent and treat it requires not only groundbreaking research but also a skilled workforce working in partnership with members of the public and community groups to translate evidence into practice. Fostering collaboration, mentorship and knowledge exchange among post-doctoral researchers, as demonstrated by the work of DEM-COMM highlighted here, is vital to ensure that research findings are adopted into practice and make a difference to the lives of people living with dementia and those who support them.

This report showcases the range of exciting research, collaborations and partnerships supported through this NIHR investment, highlighting the range of activities supporting the shifts outlined in the 10 Year Health Plan for England. This investment will ensure that research continues to inform policy, and the foundations for better care and better outcomes into the future. Thank you to everyone involved in making DEM-COMM a success.

Professor Fiona Carragher
Chief Policy and Research Officer, Alzheimer's Society

Dementia is the health and social care challenge of our time. Around one million people in the UK are living with dementia and the condition puts huge pressure on families and carers, on our NHS, social care system, and economy. At Alzheimer's Society we know that research is key to securing the breakthroughs and knowledge we need to transform the lives of people living with dementia.

This can only be achieved through the work of talented researchers, ensuring that they have the support and resources they need to turn evidence into real-world solutions. DEM-COMM has built networks, fostered collaboration and equipped post-doctoral researchers to become future leaders in dementia research.

This investment has resulted in vital new research and supported a talented cohort of researchers to remain in the field. I would like to say thank you to everyone involved in making DEM-COMM possible. Together, we are working towards a future where dementia no longer devastates lives.

Dr Jeremy Isaacs
National Clinical Director for Dementia & Older People's Mental Health

The NIHR Dementia Fellowships programme set out to do something both necessary and ambitious: to nurture a new generation of leaders who could shape the future of applied dementia research with compassion, creativity, and commitment to improving people's lives. This is an urgent task because dementia is one of the most significant public health challenges of our time. To address it requires an engaged and well-trained research community grounded in the lived realities of the condition. I had the privilege of meeting the NIHR Dementia Fellows at their 2024 and 2025 Winter Schools and saw firsthand that they possessed these qualities in abundance.

What follows is a testament not only to individual achievement but to the power of collective learning. Fellows from diverse backgrounds, disciplines, and regions came together as a community of practice—sharing ideas, challenging assumptions, and supporting one another as they stepped into leadership roles in their own research. Their projects reflect the richness of this collaboration: from innovations in mealtime care and cutting-edge data science to community-driven prevention work and digital tools designed to widen access to research.

The impact has been tangible. New partnerships have flourished, public contributors have shaped research more directly than ever, and fellows have grown in confidence and ambition. As this programme draws to a close, what remains is a vibrant network of researchers equipped with unique insights gained from their participation. Their achievements offer a hopeful path forward for dementia research—one grounded in curiosity, inclusivity, and an enduring commitment to quality and impact.

Professor Alison Richardson
ARC Wessex Director

It was a privilege to host the NIHR DEMM Com programme. As it concludes we celebrate the journey of collaboration, learning and innovation. Together the programme has built connections and advanced knowledge that will continue to shape the future of health research and the careers of those involved. And resonate far beyond the end of the programme. I invite all those involved to carry this momentum forward and continue to transform health and care for people affected by dementia through research.

Introduction

Professor Ruth Bartlett
National Lead for the NIHR Dementia Fellowship scheme, ARC Wessex, University of Southampton

The NIHR Dementia Fellowships with support from the Alzheimer's Society was a capacity-building initiative designed to prepare a cohort of post-doctoral researchers for the role of Chief Investigator in applied dementia research. A Chief Investigator (CI) plays a pivotal role in shaping the direction, integrity, and impact of a research project. Far beyond administrative oversight, a CI provides strategic leadership that ensures the research is not only methodologically sound but also relevant to practice and policy. When applied dementia research is led with clarity, compassion, and commitment, it has the power to:

- Inform evidence-based interventions that improve patient outcomes.
- Influence policy decisions that shape service provision.
- Elevate the voices of people living with dementia
- Empower practitioners with new knowledge and tools.

These fellowships provided the cohort with the time to learn and think, gain confidence, build new networks, and receive the support and inspiration they needed to become Chief Investigators in applied dementia research. The pedagogical ethos of the programme was inspired by Etienne Wenger's model of social learning. This meant that activities were designed to build not only research capacity but also a community of practice. The programme was guided by the Vitae Researcher Development Framework and aligned with the World Health Organisation's call to strengthen research capacity in applied dementia research.

The initiative ran from 1 October 2022 to 31 March 2026 and supported the development of 71 post-doctoral researchers working across England. It invested in people from a range of backgrounds working on diverse projects from big data and prevention studies to service evaluations and exploratory studies about spirituality and end-of life care. The cohort met regularly to engage in capacity and community building activities and share learning experiences.

As the NIHR Dementia Fellowships comes to an end, it is an absolute delight, as the lead co-ordinator, to showcase some of the work and successes we have had the privilege to oversee during this initiative.

R L Bartlett

Overview

Capacity-building initiatives

Three annual Winter Schools organised and hosted by ARC Wessex

12 fellows created a short video of themselves talking about their projects.

Watch here:

Two Webinar Series:

2024 | Fellow-led (7 events)

2025 | ARC Presents (15 events)

One-day joint summer meeting for NIHR Dementia Fellows and Three School Dementia Programme Grant Holders, which included a poster competition, **won jointly** by **Dr Anna Dreyer** (left in photo) and **Dr Smruti Bulsari** (right in photo).

Career conversations conducted online by **Professor Ruth Bartlett** with

28

individual fellows

Launch Day event in Southampton with special guest Professor Martin Knapp

Fellows recruited

38

interns, who supported them with their research and developed their own research skills

Crafting your narrative CV: A **writing retreat** in three parts with guest facilitator **Felicity Flynn**, Writing Skills Officer, University of Southampton.

Final Celebration event in Southampton with announcement of DEM-COMM awards winners: **Positive Influence on Practice, Outstanding Public involvement,** and **Career Progression.**

The Sandpit Grants Model

On 20th February 2024, the Alzheimer's Society and NIHR co-hosted a three-day event for NIHR Dementia Fellows. The event used the Sandpit model which involved fellows spending day one exploring and discussing challenges related to the dementia workforce, before dividing into teams to create innovative solutions to try to address some of the identified challenges.

On day two, each team worked intensively to develop and pitch a research project to address their chosen challenge.

On day three, a panel of judges heard pitches of each proposed solution from each team.

The judges' recommendations were then used by Alzheimer's Society to award funding to the successful research teams. From a total of six pitched projects, five were awarded funding. Three projects were funded in full and the remaining two projects were awarded seed funding. Total amount awarded £470,000.

	Grant Holder	Co-Investigators	Amount
Fully funded projects			
Personalising Domiciliary Dementia Care: Co-Design of an App Matching Care Preferences of Care Workers and People Living with Dementia	Dr Rasa Mikelyte, University of Kent	Dr Chris Poyner, Dr Lis Grey, Dr Katie Breheny, Dr Ilianna Lourida, Dr Daniel Soria	£110,000
AIMed: Optimising treatment regimens using computer-systems for people living with dementia	Dr Subhashisa Swain, University of Oxford	Dr Jiamin Du, Dr Nuno Tavares, Dr Jaheeda Gangannagaripalli	£224,000
DEcision-Making support Model for whole-pathway dementia workforce COMMissioning (DEMM-COMM)	Dr Joseph Kwon, University of Oxford	Dr Ting Cai, Dr Smruti Bulsari, Dr Pippa Collins, Dr Sujin Kang	£50,000
Seed funded projects			
Virtual Reality journey into dementia care	Dr Megan Rose Readman, University of Liverpool	Dr Megan Polden (Co-PI), Dr Sarah Smith, Dr Sarah Fox,Dr Annabel Farnood, Dr Olivia Luijnenburg	£43,000
The M-DROC project: Developing a Dementia Recovery College Tailored for Muslim Communities	Dr Sanda Umar Ismail, University of Liverpool	Dr Emmanuel Nwofe	£43,000

External Funding Awarded To Fellows

As Chief investigator	£2,381,989 (68% success rate)
As Co-investigator	£15,529,728 (45% success rate)

Publications

110+

Number of public contributors involved in projects

70+

During his fellowship, Dr Chris Poyner, ARC West Midlands, established a new group of public contributors, known as DEMCARE - the Dementia and Social Care Group. Some members joined us at the Winter School 2025 to share their experiences of being involved in applied dementia research.

Selected Highlights

Innovations in care

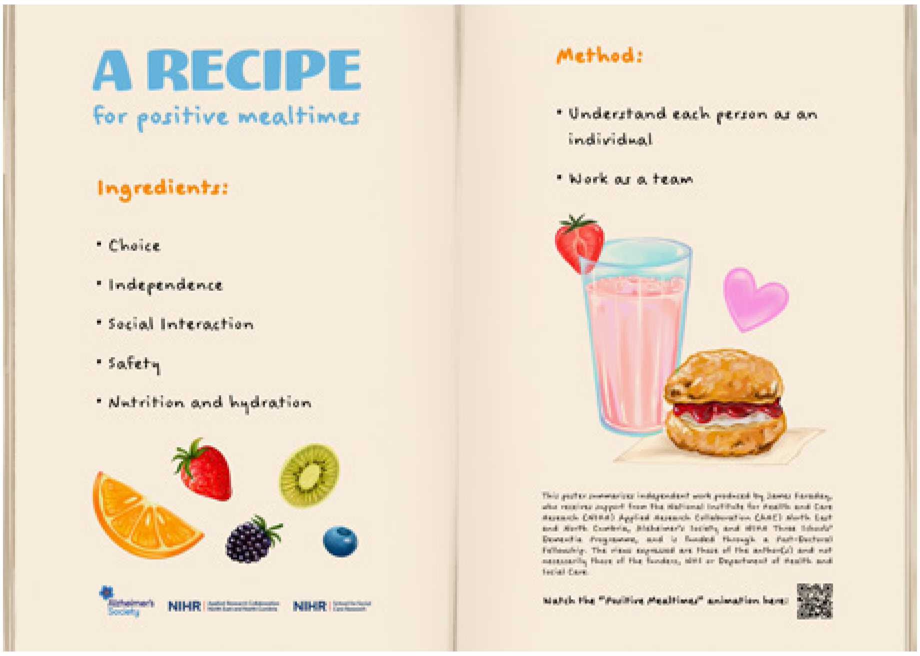
Dr James Faraday: ARC North East and North Cumbria, Population Health Sciences Institute, Newcastle University, Adult Speech and Language Therapy, The Newcastle upon Tyne Hospitals NHS Foundation Trust, UK.

Mealtime care for people living with dementia in care homes.

James' fellowship focused on making mealtimes better for people living with dementia in care homes. Mealtimes are fundamental to health and quality of life. But some people living with dementia may experience challenges at mealtimes, such as problems recognising food and drink, or reduced range of tastes and preferences, or swallowing difficulties. Good mealtime care can transform the experience of people with dementia living in care homes.

Before the fellowship, James worked with care home staff to develop a training package on mealtime care. During the fellowship, James' main objectives were to: (1) test the training in care homes to see if it improved staff confidence and worked in a busy care environment (2) find effective ways to share good practice widely. He achieved these objectives by:

- Conducting a feasibility study in three care homes, gathering feedback that improved the training's content and format for wider rollout.
- Leveraging NIHR Three Schools funding, in collaboration with care home communities and Roots and Wings to create additional resources, including:
    - An animation – 'A Recipe for Positive Mealtimes'.
    - A video – 'Making a Difference Through Dementia Research'. **Watch here:**



A RECIPE
for positive mealtimes

Ingredients:

- Choice
- Independence
- Social Interaction
- Safety
- Nutrition and hydration

Method:

- Understand each person as an individual
- Work as a team

This poster summarises independent work produced by James Faraday, who receives support from the National Institute for Health and Care Research (NIHR) Applied Research Collaboration (ARC) North East and North Cumbria, Alzheimer's Society and NIHR Three Schools' Dementia Programme, and is funded through a Post-Doctoral Fellowship. The views expressed are those of the author(s) and not necessarily those of the funders, NIHR or Department of Health and Social Care.

Watch the "Positive Mealtimes" animation here:

The team also produced online posters to support these resources.

James recruited and supported intern, Jakarin Ali, to work on the project. Jakarin reviewed the literature on implementing training in care homes and presented findings at a conference.

Impact and Benefits

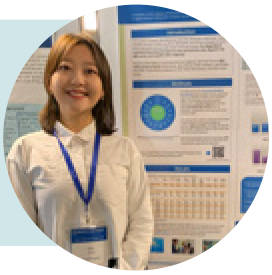
The fellowship enabled James to collaborate with care home managers, staff, and residents, ensuring his research was relevant and valuable. This led to an improved training package and freely available online resources that promote good mealtime care practices for all care homes.

The fellowship also enabled James to develop research leadership skills and publish two articles from his PhD on mealtime care.

Scan the QR code to view the one that is open access.

Building data capabilities

Dr Lin Gong: ARC Yorkshire and Humber,
University of Leeds



Intersectional disparities in modifiable risk factors for dementia: A UK population-based cohort study.

Dementia cases within some minoritised ethnic groups are projected to increase by up to fifteen-fold in the coming decades. Without a clearer understanding of their risk profiles and prevention needs, these populations are likely to continue experiencing later diagnosis, poorer risk-factor control and reduced access to support, ultimately driving avoidable NHS costs and widening inequalities.

Lin's fellowship involved using data from Connected Bradford – a dataset that links routine electronic data across primary care, secondary care, community care and social care for over 800,000 citizens in the Bradford district, UK. Participants include patients aged over 45 with and without a diagnosis of dementia between 2009 to 2019. The study examines how 14 modifiable risk factors are associated with dementia, across eight different ethnic and socioeconomic groups. It uses multiple regression models to explore these relationships and identify which factors may contribute most strongly to disparities in dementia risk. Results will support the design of culturally tailored prevention strategies and inform public health planning.

During her fellowship, Lin worked in partnership with NIHR Dementia Fellows – Dr Amirah Akhtar, Dr Emmanuel Nwofe, Dr Sudha Raman, and Dr Magda Oliveira Jordao to stimulate a data-driven approach to dementia prevention within diverse communities. They worked together to:

- Develop and deliver three community-facing dementia-prevention events in Leeds and Bradford. Events were aimed at people from South Asian, East Asian, and Black African communities and attracted more than 130 participants. The events helped to raise awareness that dementia can be prevented and highlighted common risk factors such as high blood pressure, diabetes, and depression.
- Engage with Leeds City Council about how to promote dementia prevention at a community level, helping to increase awareness of wider environmental risks, such as air pollution.

Impact and Benefits

The fellowship enabled Lin to develop advanced skills in analysing large-scale electronic health records, including SQL, R, multiple imputation and reproducible workflows. Moving from a social science background into applied dementia research, she has built the technical capability needed to lead robust quantitative research on dementia prevention studies.

> Results will support the design of culturally tailored prevention strategies and inform public health planning.

Lin strengthened her ability to communicate complex analytical findings in clear and accessible ways for diverse audiences. She built meaningful working relationships with a wide range of stakeholders and developed practical skills in adapting quantitative evidence for community, policy and practice audiences. She mentored an intern and provided peer support to early-career researchers. Contributing to others' development strengthened research capacity within her team and supported her growth as an emerging research leader in applied dementia research.

Scan the QR code for more details of Lin's work.

Achievements

DEM-FEST

With support from ARC Wessex, fellows organised a National Festival of Applied Dementia Research (DEM-FEST) during Dementia Action Week - an event organised by the Alzheimer's Society (19-25 May 2025).

It was the first time Dementia Action Week included a research component.

DEM-FEST hosted 22 events across England: 20 in person, and two online. All events were aimed at people either concerned about, or living with dementia, including family carers. They provided an opportunity for fellows to develop their communication and networking skills. Two events were specifically for people from South Asian communities, and one event for people from Afro-Caribbean Communities. Seven events were also aimed at service providers, researchers, and health and social care professionals. Events were wide-ranging and included a film screening, community events, art exhibition, a tea dance, chair-based Yoga, and a Walking football session.

An impressive

939

attendees took part in DEM-FEST - an encouraging sign of growing community involvement and relevance of applied dementia research.

Scan the QR code for more detailed information

Ethics Resource

During the first Winter School, fellows - Dr Lis Grey, Dr Olivia Luijnenburg and Dr Rasa Mikelyte designed and led a session called *Navigating the Ethical Maze*. The session built on the 'Ethics and Dementia research' webinar held in 2024 as part of the fellow-led webinar series.

The idea behind the resource was to map potential solutions to ethical challenges faced in dementia research, and to consider issues faced across the research lifecycle - from initial PPI work and protocol development through recruitment and data analysis to dissemination of findings.

Scan the QR code for more details and to download a copy of the resource

Special Interest Groups

In year 1 the cohort organized themselves into 12 Special Interest Groups (SIGs) to enhance cross-ARC collaboration and shared learning in relation to a specific research area.

Each SIG had a designated lead and £2,000 budget. The SIGs contributed through a range of notable activities and achievements, as outlined in the table below.

Name: Learning Disabilities

Lead: Dr Tamlyn Watermeyer

Notable activity and achievement: Networking with other learning disability groups and presenting work at outreach events. Poster presented at Alzheimer's Association International Conference and articles planned.

Name: Equality, diversity, and inclusion

Lead: Dr Marie Poole

Notable activity and achievement: Sharing experiences, ideas, networks, and learning how each other's work intersects and differs. SIG member, Dr Kumud Kantilal, wrote a blog and co-produced a pamphlet on Caring for a Relative With Dementia.

Name: Palliative and End-of-Life

Lead: Dr Tomasina Oh

Notable activity and achievement: Co-producing an article titled "Assisted dying: thoughts from someone living with dementia" for AGENDA- the British Geriatric Society members' magazine.

Name: Care Home Practice

Lead: Dr Tamara Backhouse

Notable activity and achievement: Collaborating with the Cross-ARC Care Homes Network and ENRICH to deliver a national webinar 'Making a difference through dementia research'.

Name: Primary Care Network

Lead: Dr Pallavi Nair

Notable activity and achievement: Consolidating a cross-institutional network of researchers interested in dementia within primary care settings. Dr Nair formed a Dementia Tapestry Working Group, part of the Octopus model in Westminster. **Scan QR code for more details.**

Name: Brain Health and Dementia Prevention

Lead: Dr Sarah Smith

Notable activity and achievement: Sharing knowledge within the group; members presenting at the INTERDEM Prevention Taskforce Meeting.

Name: Dementia and multiple long-term conditions

Lead: Dr Lis Grey

Notable activity and achievement: Hosting a webinar with a guest speaker and supporting each other with grant writing. Applied to the NIHR Team Science Award Scheme (unsuccessful).

Name: Health Data Sciences

Lead: Dr Ting Cai

Notable activity and achievement: Researching and writing a literature review on: 'Applied dementia research using electronic health record data: utilisation, advantages and challenges'

Name: Digital Health

Lead: Dr Jaheeda Gangannagaripalli

Notable activity and achievement: Writing a scoping review and planning workshops to involve the public in research.

Name: Realist Approaches In Dementia – Evaluation and Research (RAID-ER)

Lead: Dr Hannah Wheat

Notable activity and achievement: Hosting an in-person symposium at the University of Plymouth, leading to a published blog. Applied to the NIHR Team Science Award Scheme (successful).

Name: Creative Health

Lead: Dr Sarah Fox

Notable activity and achievement: Hosting a workshop attended by researchers, people with lived experience, and creative practitioners. Invited to merge with the British Society of Gerontology creative health SIG.

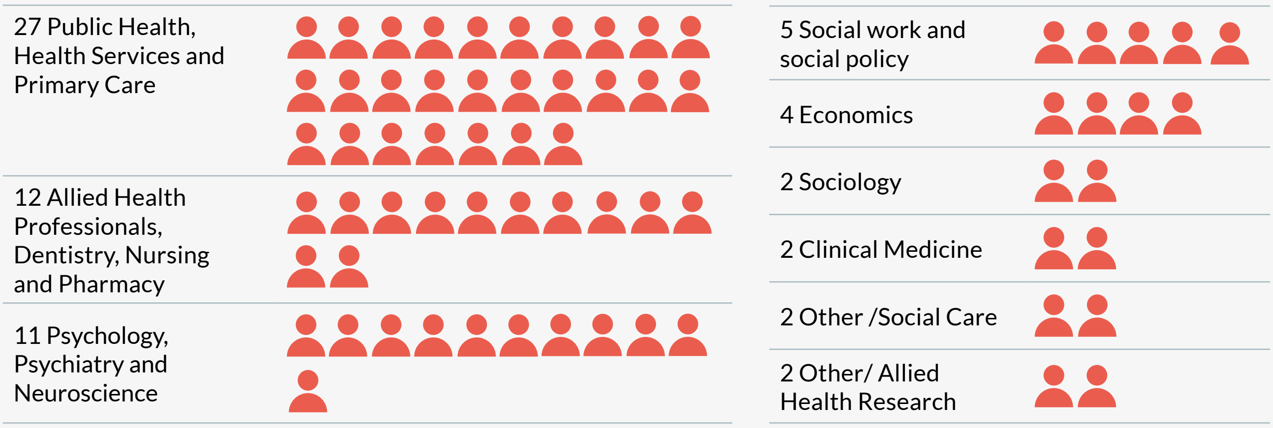
Name: Research and Practice in Homecare

Lead: Dr Gladys Yinusa

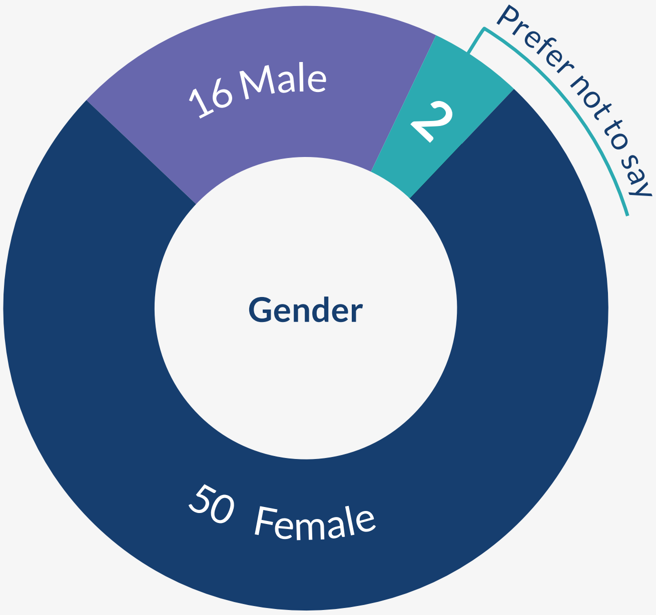
Notable activity and achievement: Hosting a hybrid event on 'Readiness in Homecare | Strengthening Partnerships Between Providers and Researchers for Better Outcomes'. Dr Yinusa invited to serve on the judging panel for the National Home Instead HG Recognition Awards.

Equality, Diversity and Inclusion

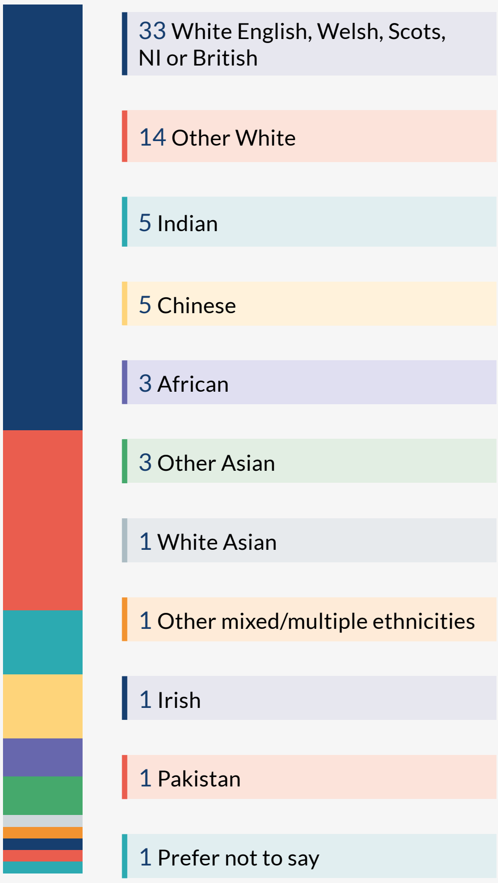
Academic backgrounds



- 27 Public Health, Health Services and Primary Care
- 12 Allied Health Professionals, Dentistry, Nursing and Pharmacy
- 11 Psychology, Psychiatry and Neuroscience
- 5 Social work and social policy
- 4 Economics
- 2 Sociology
- 2 Clinical Medicine
- 2 Other /Social Care
- 2 Other/ Allied Health Research



Ethnicity

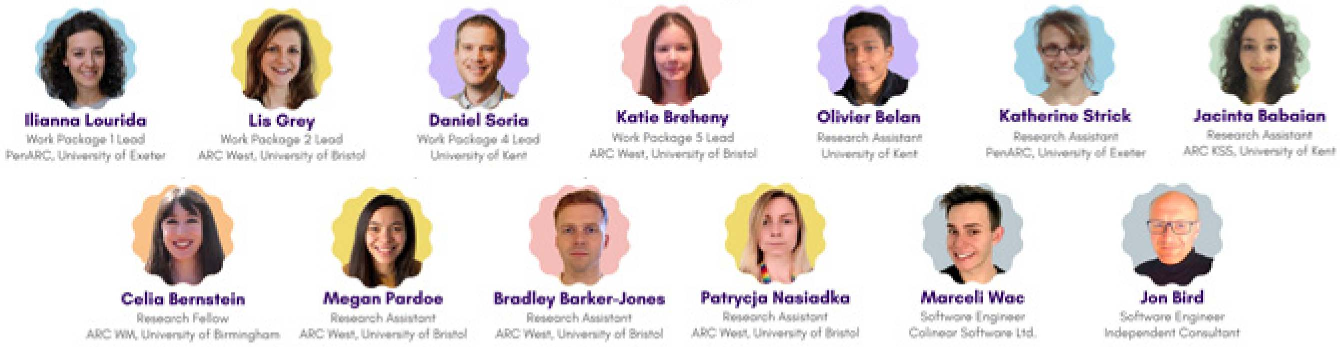


- 33 White English, Welsh, Scots, NI or British
- 14 Other White
- 5 Indian
- 5 Chinese
- 3 African
- 3 Other Asian
- 1 White Asian
- 1 Other mixed/multiple ethnicities
- 1 Irish
- 1 Pakistan
- 1 Prefer not to say

NHS 10 Year Health Plan for England

From hospital to community

Lead Researchers: Dr Rasa Mikelyte, Dr Chris Poyner and team.



Ilianna Lourida
Work Package 1 Lead
PenARC, University of Exeter

Lis Grey
Work Package 2 Lead
ARC West, University of Bristol

Daniel Soria
Work Package 4 Lead
University of Kent

Katie Breheny
Work Package 5 Lead
ARC West, University of Bristol

Olivier Belan
Research Assistant
University of Kent

Katherine Strick
Research Assistant
PenARC, University of Exeter

Jacinta Babaian
Research Assistant
ARC KSS, University of Kent

Celia Bernstein
Research Fellow
ARC WM, University of Birmingham

Megan Pardoe
Research Assistant
ARC West, University of Bristol

Bradley Barker-Jones
Research Assistant
ARC West, University of Bristol

Patrycja Nasiadka
Research Assistant
ARC West, University of Bristol

Marceli Wac
Software Engineer
Colinear Software Ltd.

Jon Bird
Software Engineer
Independent Consultant

Personalising Domiciliary Dementia Care

Delivering high-quality home-based care for people living with dementia can be challenging. Every person's needs and preferences are different, and care providers must balance these with care worker skills and availability. This project aimed to personalise dementia home care by co-designing a digital application (app) that matches care workers according to a client's preferences (e.g. shared interests) and carer skills. The app then makes schedules that support continuity of care while respecting staff working patterns.

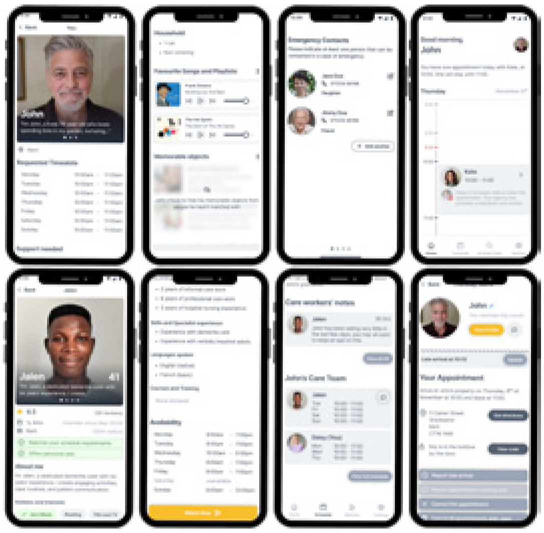
We co-designed an app with people who are supported by, deliver, and manage domiciliary care. We engaged people living with dementia, family carers/supporters, care workers, and care managers throughout the project. Together, we explored what 'good' domiciliary dementia care looks like, identified practical challenges, and iteratively developed both the app's matching process and appearance to reflect real-world needs.

The work supports the NHS priority of moving care from hospitals into the community by making home based dementia care more personalised. Our app helps to ensure that people living with dementia receive care suited to their individual needs and preferences, potentially reducing the risk of unnecessary hospital admission and chance of readmission. When someone is regularly supported by care workers who know the person's needs, care workers are better placed to notice and respond to small changes in wellness, avoiding the need for hospital care.

The app balances care continuity with care workers' hours and minimizes travel time. Combined with good client-carer matching, this can improve workforce retention—essential for high-quality dementia care and reducing reliance on hospitals.

Our project shows that co-designed, preference-based matching and scheduling tools are feasible and valued. Treating prototype development as research enabled iterative input from people with lived and professional experience, ensuring real-world relevance. This approach highlights how continuity and fair scheduling enhance experiences for people with dementia, families, and care workers, while also revealing tensions and competing priorities—underscoring the need for transparency and ethics in person-centred technologies.

Next, we aim to share findings widely and partner with home care scheduling providers to test the app in real settings, capturing experiential and economic benefits for people with dementia, families, staff, and provider organisations.



Supporting the NHS Plan

From sickness to prevention

Lead Researcher: Dr Sanda Umar Ismail, with Professor Heather Brown, Dr Faraz Ahmed, and Professor Carol Holland

Reducing dementia risk in faith communities

Dementia is a growing public health challenge, but many cases could be delayed or prevented by addressing everyday factors that increase risk. Although more than half of people in England identify with a faith community, no research has explored how dementia risk factors appear within these groups. Faith communities often have unique social structures, such as strong social ties, shared routines, and collective health norms, that may influence both exposure to risk and opportunities for prevention. This project examined national data from older people in England to compare 14 known dementia risk factors in people with and without a religious affiliation. By analysing these patterns, we aimed to understand which risks are most important in each group.

The study found that depression, social isolation, hearing loss, and vision problems were the biggest contributors to dementia risk in faith communities. In non-faith groups, depression, social isolation, high cholesterol, and low education were more prominent. These differences show that dementia prevention cannot take a "one-size-fits-all" approach. This work benefits older people, families, community organisations, and health services by highlighting how faith settings and groups with similar structures can play a powerful role in supporting brain health across society.

> "Dementia prevention cannot take a 'one-size-fits-all' approach."

This project directly supports the NHS priority, From Sickness to Prevention, by identifying where dementia risk can be reduced. Instead of focusing on treatment, the study highlights that understanding which risks matter most to which communities can enable the NHS and local services to design earlier, more targeted prevention programmes. For example, the findings show that depression is the leading preventable risk factor for dementia in both faith and nonfaith groups, yet it often goes undiagnosed and untreated in older adults. This underlines the need for better mental health support and earlier intervention.

The study also shows that hearing and vision problems are especially common in faith communities, suggesting opportunities for community-based screening, improved access to hearing or visual aids, and health promotion delivered through trusted local groups.

Importantly, the research demonstrates that faith communities and settings with similar social structures, such as exercise groups, hobby clubs, and other community spaces, can play a vital role in supporting social connection, raising awareness, and reducing risks. This helps the NHS shift towards a preventative model that keeps people healthier for longer and reduces future demand on services.

The next step will involve exploring these patterns within specific faith communities to ensure prevention strategies reflect the unique needs and cultural contexts of different groups. These efforts can support earlier identification of risk, help people maintain brain health for longer, and guide more effective, prevention-focused approaches across the NHS and community settings.

From analogue to digital

Lead Researcher: Dr Tamlyn Watermeyer,
North East and North Cumbria ARC

Revolutionising Alzheimer's disease assessment in Down syndrome (The RAD research programme)

People who have Down syndrome are at high risk of developing Alzheimer's disease as they get older. Yet, there are very few chances for this group to take part in dementia research, This means families often miss out on early detection, better support, and access to new developments in care. Even worse, testing for cognitive impairment for people with Down syndrome remains in the dark ages, with many tools being unsuitable or inflexible to their physical abilities and neurodiversity.

This project is testing novel engaging game-like digital tools that can be used at home or in local community settings to check memory and other thinking skills in adults with Down syndrome. Instead of long paper-and-pencil tests in hospital clinics or universities, people can take part using their computer or tablet, with support if needed.

By using assessments that are engaging, comfortable, and accessible, the project has successfully piloted a suite of digital tools with people with learning disabilities. The tools have been shown to spot early changes linked to Alzheimer's disease sooner in the general population. It is hoped that this can improve dementia diagnosis for learning disability populations and help families plan ahead, seek support earlier, and inform services about what works best for this high-risk but often overlooked group.

This work supports the NHS priority of moving from Analogue to Digital. Instead of relying on paper tests done in specialist hospital clinics, we piloted digital tools. The digital tools are on an iPad or laptop and involve asking people to play games, or to press symbols as fast as they can depending on what numbers are flashing. Replacing paper forms with digital activities gives instant, accurate scores on thinking and memory skills. This allows researchers and clinicians to review results remotely and update tools easily in light of patient feedback or new evidence.

> To date, 33 people with Down syndrome have piloted the games, rating them highly for enjoyment.
>
> **Average score**
>
> **9/10**

To date, 33 people with Down syndrome have piloted the games, rating them highly for enjoyment (average score 9/10). We found that completion rates were higher for digital tools than traditional pen-and-paper tasks; presumably because the digital tools do not require verbal responses and can accommodate dexterity issues, common in learning disability communities. Importantly, we found on one of the measures that performance on this task was associated with more variability in performance on a composite of "gold-standard" cognitive assessments for people with Down syndrome. This suggests initial validity of the measure to detect possible cognitive changes.

The projects shows that it is both possible and acceptable to use digital cognitive tools with adults who have Down syndrome. Individual feedback from participants for these game-like tests have been highly favourable and families have reported that taking part at home or in the community feels less stressful and more dignified than travelling to hospital-based clinics or universities. Next steps involve refining these digital tools, expanding the suite to include technologies to assess sleep disturbances and mobility, known risk factors for developing dementia, but little studied in Down syndrome.

Directory of Researchers by Host ARC

as of August 2025

Esther Loseto-Gerritzen

Project focus: Explore the needs of people with Young Onset Dementia in terms of care and technology.

ARC: East Midlands

Neil Chadborn

Project focus: Access to technology and needs of peoplefrom diverse ethnic and socioeconomic backgrounds.

ARC: East Midlands

Orri McDermott

Project focus: Addressing unmet needs of people living with young onset dementia.

ARC: East Midlands

Anna Dreyer

Project focus: Social determinants in cognitive impairment and dementia.

ARC: East of England

Greg Windle

Project focus: Investigating dementia-friendly communitycare in the East of England.

ARC: East of England

Megan Davies

Project focus: Prehabilitation/ rehabilitation in care homes for those with dementia.

ARC: East of England

Smruti Bulsari

Project focus: Research on dementia strategies.

ARC: East of England

Tamara Backhouse

Project focus: Optimising personal care assistance for people with advanced dementia.

ARC: East of England

Julieta Camino

Project focus: understanding the availability of interventions that exist to provide carers with the information they need to support their family members on daily activities.

ARC: East of England

Emma Elliott

Project focus: Deconditioning in hospital-based patients with dementia.

ARC: Greater Manchester

Sarah Fox

Project focus: Everyday aesthetics and the intersection of arts and health.

ARC: Greater Manchester

Sarah Smith

Project focus: Physical activity and dementia prevention.

ARC: Greater Manchester

Jaheeda Gangannagaripalli

Project focus: Digital technologies for falls preventions for people with dementia.

ARC: Greater Manchester

Barbora Silarova

Project focus: Supporting wellbeing, quality of life and access to services for those with dementia living alone or in hard-to-reach areas and their unpaid carers.

ARC: Kent, Surrey and Sussex

Rasa Mikelyte

Project focus: Integration of services for seamless dementia care.

ARC: Kent, Surrey and Sussex

Sarah Polack

Project focus: Supporting well-being for people with dementia in deprived coastal communities/rural populations.

ARC: Kent, Surrey and Sussex

Georgia Bell

Project focus: Loneliness and dementia.

ARC: Kent, Surrey and Sussex

Alessandro Bosco

Project focus: Dementia and palliative/end of life care.

ARC: Kent, Surrey and Sussex

James Faraday

Project focus: Mealtime care for people living with dementia in care homes.

ARC: North East & North Cumbria

Marie Poole

Project focus: Role of integrated care and sporting clubs for people from socially disadvantaged backgrounds.

ARC: North East & North Cumbria

Steven Lyons

Project focus: Investigating how music provides opportunities for residents in care homes to live healthy lives, build relationships and maintain independence and dignity.

ARC: North East & North Cumbria

Tamlyn Watermeyer

Project focus: Involving people with Learning Disabilities in dementia research & care through technological solutions.

ARC: North East & North Cumbria

Connor Richardson

Project focus: An investigation into the effects of anti-inflammatory medication have on risk of in life dementia and pathology in a population representative cohort age 65 years and over using the CFAS population.

ARC: North East & North Cumbria

Alex Tsui

Project title: Acute care of people living with dementia.

ARC: North Thames

Esther Hui

Project focus: Risk factors for dementia prevention.

ARC: North Thames

Kumud Kantilal

Project focus: Living with dementia and other health conditions.

ARC: North Thames

Claudio Dilorito

Project focus: Promoting uptake and continued use of social care in people with dementia who live alone and have no informal support (SoCeeD).

ARC: North Thames

Laura Prato

Project focus: Dementia care navigators.

ARC: North West Coast

Megan Polden

Project focus: Examining the impacts of singing support services for people living with dementia and their carers on well-being, quality of life, social isolation and loneliness.

ARC: North West Coast

Megan Readman

Project focus: Parkinson's disease dementia and link with hearing loss.

ARC: North West Coast

Sanda Ismail

Project focus: Religiosity and spirituality in risks of cognitive frailty and dementia.

ARC: North West Coast

Roxanna Korologou-Linden

Project focus: Blood-based biomarkers and proteomics for brain ageing and cognitive decline.

ARC: Northwest London

Sujin Kang

Project focus: Cognitive Health in Ageing Register: Investigational, Observational, and Trial Studies in Dementia Research (CHARIOT): Prospective Readiness cOhort Study(PRO).

ARC: Northwest London

Pallavi Nair

Project focus: identification and support of individuals with dementia and mild cognitive impairment in the community setting by community health and wellbeing workers.

ARC: Northwest London

Caroline Potter

Project focus: Exploring the availability and effectiveness of community-based support for enabling people to maintain health and wellbeing following initial diagnosis of dementia or its precursor (MCI).

ARC: Oxford and Thames Valley

Jiamin Du

Project focus: Early diagnosis of dementia and real-world data.

ARC: Oxford and Thames Valley

Padraig Dixon

Project focus: Understanding the cost-effectiveness of drug therapies (particularly repurposed drug therapies) to prevent and treat condition.

ARC: Oxford and Thames Valley

Subhashisa Swain

Project focus: Biological ageing in dementia and multimorbidity trajectories and clusters.

ARC: Oxford and Thames Valley

Ting Cai

Project focus: Exploring preventive medications for dementia: big-data based pharmacoepidemiological research.

ARC: Oxford and Thames Valley

Joseph Kwon

Project focus: Whole-disease economic modelling of dementia prevention and care.

ARC: Oxford and Thames Valley

Megan Kirk-Chang

Project focus: Intervention-based prevention strategies for dementia, including dietary modification.

ARC: Oxford and Thames Valley

Annabel Farnood

Project focus: Empowering better end of life dementia care for family carers of people with dementia' (EMBED-Care4FamilyCarers).

ARC: South London

Directory of Researchers by Host ARC

as of August 2025 (continued)

Lesley Williamson

Project focus: Using routine data to understand and improve health and social care for people with dementia near the end of life.

ARC: South London

Olivia Luijnenburg

Project focus: Spirituality in residential care for people living with dementia: implementing reflective tools for care workers of people living with dementia.

ARC: South London

Catherine Alexander

Project focus: working with the IDEAL project team and helping to develop tools for use by people with dementia.

ARC: South West Peninsula

Ilianna Lourida

Project foucs: Dementia risk factors and added dementia home care following a sandpit funding in summer 2024.

ARC: South West Peninsula

Tomasina Oh

Project focus: Continuity of health and social care and advance care planning influence unplanned or unwanted high-level care for people with dementia and other long-term conditions, particularly for underserved groups.

ARC: South West Peninsula

Hannah Wheat

Project focus: Evaluation of the D-PACT intervention and ENLIVEN, a project focused on small businesses making the wellbeing benefits of outdoor activity more accessible to older people with cognitive impairments.

ARC: South West Peninsula

Catherine Murphy

Project focus: Dementia and continence management: Supporting homecare workers.

ARC: Wessex

Gladys Yinusa

Project focus: TOMATO: nuTritiOn and deMentia AT hOme.

ARC: Wessex

Pippa Collins

Project focus: An ethnographic exploration into the work of caring for paid homecare workers.

ARC: Wessex

Nuno Taveres

Project focus: Exploring the self-management process of other long-term conditions in people living with Dementia.

ARC: Wessex

Lis Grey

Project focus: Valuation of a Parkinson's Treatment Hub and development of dementia interventions and evaluation tools to support people from diverse communities.

ARC: West

Katie Breheny

Project focus: To improve use of preference-based outcome measures in the economic evaluation of interventions for people with dementia.

ARC: West

Natasha Woodstoke

Project focus: Supporting families to adjust to a diagnosis of dementia: Adapting the LivDem intervention.

ARC: West

Suzanne Molesworth

Project focus: Dementia's place within the developing ICS/ICB landscape/multidisciplinary approaches.

ARC: West Midlands

Chris Poyner

Project focus: People living with Dementia and informal carer/family experience within a social care context.

ARC: West Midlands

Paul Campbell

Project focus: Social care practice.

ARC: West Midlands

Amirah Akhtar

Project focus: Promoting healthy lifestyles to reduce dementia risk factors in minority ethnic communities.

ARC: Yorkshire and Humber

Emmanuel Nwofe

Project focus: Dementia prevention and modifiable risk factors within Minority Ethnic communities.

ARC: Yorkshire and Humber

Lin Gong

Project focus: Dementia prevention and health inequalities among different ethnical groups.

ARC: Yorkshire and Humber

Sudha Raman

Project focus: Identifying risk factors for dementia and cognitive decline in post-TIA/post-stroke.

ARC: Yorkshire and Humber

Special thanks for our Programme Management Group:

Adam Smith
Alice Clarkson
Alison Richardson
Amy Bell
Catherine Bowen
Charlie Minter
Danielle Wilson
Eneida Mioshi
Esther Hui
Hannah Wheat
Jackie Bridges
Karen Fernando
Kieran Lee
Lis Grey
Lucy Devendra
Martin Knapp
Naoko Kishita
Pam Holloway
Rae Tobin
Ruth Bartlett
Siân Gregory
Val Mann