



1 year of the Dementia Lived Experience Group

March 2024 - March 2025

In partnership with:



IMPERIAL



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Celebrating the Dementia Lived Experience Group

The Dementia Lived Experience Group was set up as a strategic advisory group to the UK Dementia Research Institute's Care Research & Technology Centre (UK DRI CR&T) in March 2024.

The aim of the Group was to ensure the Centre's research remains person-centred, inspire and connect researchers, act as a critical friend, advocate for change and drive real-world impact.

As the Group's first year comes to an end,

we celebrate their achievements in not only impacting the research of the Centre, but helping evolve the cadence, rhythms and rituals of the Group.

It is with enormous gratitude we say thank you to our members for being a part of the first chapter of this journey:

Anna Ferguson Montague, Anne Farthing, Carol Harris, Florence Young, Maria Connolly, Maria Okosieme, Martin Robertson, Mary Greensite, Rosalind Duhs, Ruth Geall, Sam Pearce-Kearney, Shelley Hastings, Sittana Abdelmagid, Sue Boex, Susan Williams-Joseph



“The Dementia Lived Experience Group has made a major contribution to the Care Research & Technology Centre by helping us ensure everything we do is focused on improving the lives of people affected by dementia.”

— Professor David Sharp, CR&T Centre Director

The Dementia Lived
Experience Group's

IMPACT IN NUMBERS



11

projects
contributed
to across the
Centre

439

hours of
involvement

5

funding bids
supported

16 members

1

'Involvement Officer' role created

8

individual
researchers
supported

2

contributions to
Institute-wide
projects

3

CR&T monthly meetings attended,
contributing to strategic workshop
discussions and developments

Supporting researchers across the Centre

Group members have supported 11 projects and over 8 individual researchers across the Centre. This has included group discussions on research projects brought to the Lived Experience Group meetings as well as off-line collaborations working directly with researchers.

Projects have included EEG in delirium detection, a scoping review on AI in Occupational Therapy and analysing an at home video sleep study.

Members have also attended Centre-wide workshops, impacting discussions on radar and the use of chat bots in dementia care.



“Presenting our forthcoming ‘At-Home Video study’ to the Dementia Lived Experience Group was a highly valuable step in developing our Protocol. After discussion with the group, we revised our inclusion/exclusion criteria and privacy and dignity considerations.

I was very pleased to see the enthusiasm to go for a larger and longer study! The feedback from the group undoubtedly helped us receive only minor reviewers’ comments from our Ethics submission, despite the perceived controversy surrounding the use of video as a recording medium.”

— Prof Kevin Wells, researcher at the University of Surrey



Shaping & securing future funding

Group members have contributed to **x5 grant applications** in the past year. In each application, they have helped **ensure the research is person-centred**; humanising language, advocating for more supportive methodologies, challenging inclusion/exclusion criteria, and co-designing Public Involvement strategies.

Fellowship applications

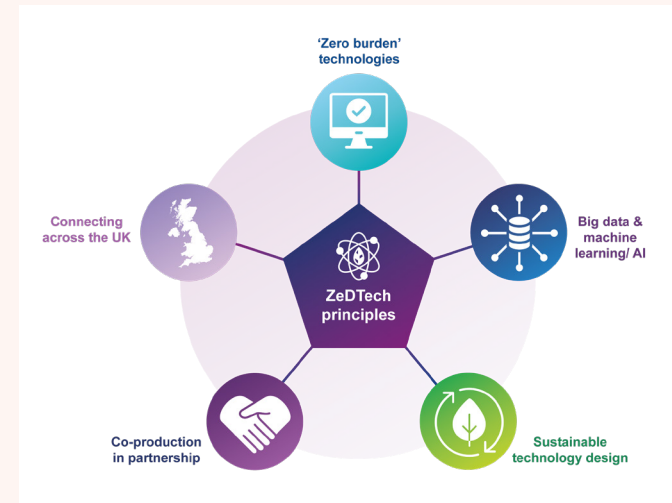
x2 members helped shape Julian Jeyasingh Jacob's NIHR Fellowship application, aiming to "Improving Dementia Care with Digital Tools".

Clinical trials

x2 members reviewed Prof Marcus Drake's clinical trial application; aiming to reduce antibiotic prescriptions for urinary tract infections (UTI's) and understand how infection affects neurodegeneration.

Network grants and supporting funding for public involvement roles

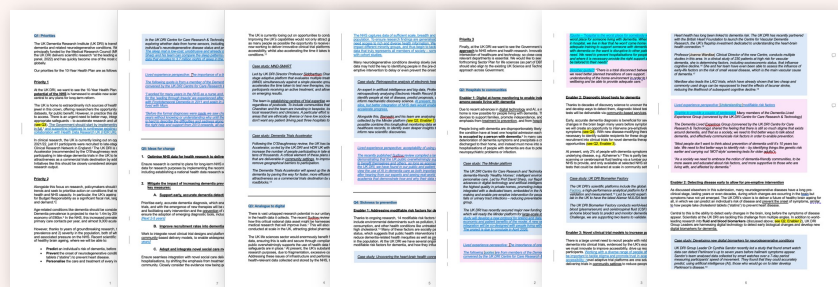
x2 members helped secure £1.6m funding for "ZeDTech", a network grant aimed to use "zero-burden" technologies to advance independent living. This funding will support future involvement of the group and has helped fund a full time PPIE officer to support involvement activities in the Centre.



Successful £1.6m EPSRC Network Plus grant proposal: "ZeDTech"

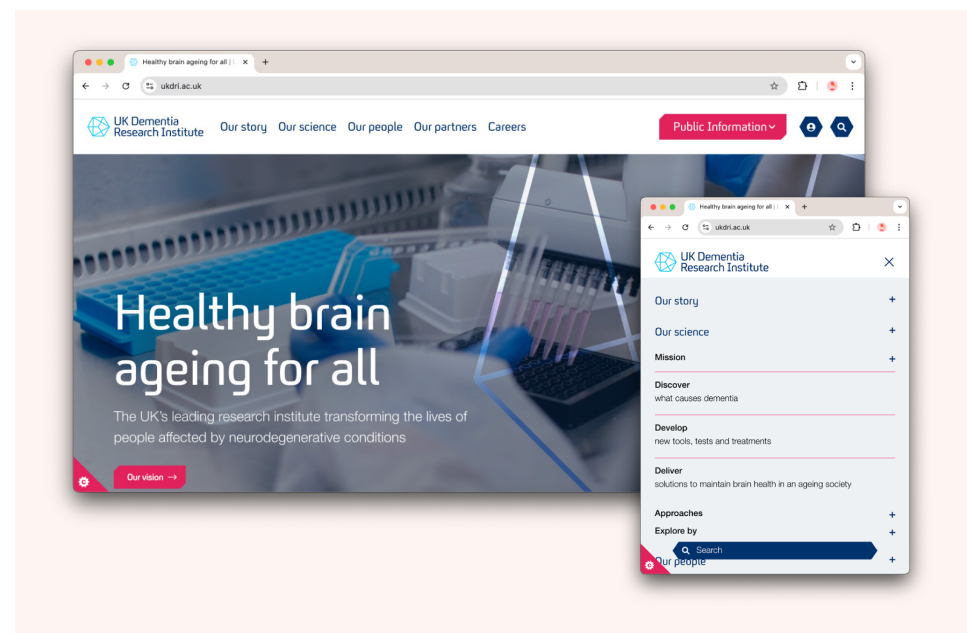
"The Dementia Lived Experience Group has significantly influenced our work at the Centre. Their insights and contributions have been invaluable, providing essential insights that have helped shape our research and enriched our grant proposals and fellowship applications with real-world perspectives."

— Julian Jeyasingh Jacob,
Occupational Therapist



Impacting NHS Change

In late 2024, the UK Government put out an open call as part of the development of their 10 Year Health Plan. We ran a session with the Lived Experience Group to understand what was felt as the greatest needs of people living with dementia. Their insights (highlighted in pink above) fed into the Institute-wide submission, ensuring the needs of people affected by dementia remain at the heart of research and funding priorities.



Shaping the UK DRI website

In early 2024, x3 members helped shape the UK DRI website re-design. The group shaped the language and imagery used on the website, reviewed navigation accessibility, and helped form the new "Public Information"; considering its purpose and most relevant information to include. The site launched in Dec 2024.



A selection of 'work-in-progress' documents showing the collaborative processes across the working groups.

Working project groups

MinderCare

5 members have joined MinderCare; a project translating the Minder study into a real-world NHS service. Members have shaped the format, design and language of on-boarding materials and assessments, and are working to define outcome measures for a clinical trial.

Designing Tech for Dementia Care

5 members are developing a guide for researchers on the needs of people affected by dementia in technology design. The group have co-produced the process and are creating a public survey to gain UK-wide insights on needs.

Friends of CR&T Event V2

4 members are working to develop the public engagement strategy for the Centre. Identifying the need for clear communications materials, they are co-authoring a 'living' document to use.

Bringing Lived Experience to the heart of our research

In October 2024, 7 Lived Experience Group members shared their stories at the regular Centre monthly meeting. The meeting was attended by over 60 staff members from across different specialisms in the Centre.

The session was co-designed and co-facilitated by 2 members of the Group. The aim of the session was to help researchers understand different real-world lived experiences of people

affected by dementia, and help them consider the relevance of their research in relation to the stories shared.

What impact did the session have?

“Hearing the range of speakers but also the small details was a powerful reminder of the range of experiences...so powerful I’m a bit lost for words as I process it all”

“Struck me the incredible commitment and kindness of the group. It was really moving and important to hear”

“Such a great session, and so inspiring! Keep doing them, they are so important”



Sharing stories of lived experience with the Centre.

“The group have made a significant impact on the centre in their first year. They have brought the lay perspective and constructive curiosity to our multi-disciplinary centre meetings, improving understanding throughout the organisation. They

have influenced new project proposals and funding applications, and they have reminded us of the purpose of our mission by sharing their personal experiences and reflections so generously.”

— Matthew Harrison,
Head of Design, CR&T

“I believe the members of the Dementia Lived Experience Group have opened the eyes of researchers in the centre, to help them understand what it really means to live with dementia, and have made the research more human-centred and relevant to the needs of those affected.

Their wealth of experience has helped shape successful funding applications and guide the selection of research priorities. Additionally, this group has been instrumental in improving the way we communicate research; not only to the wider public, but also within the centre itself, which is highly multi-disciplinary.”

— Lina Aimola, Project Manager
at the UK DRI Care Research & Technology Centre