



DEM-FEST REPORT 2025

Data and feedback collected from the National Festival of Applied Dementia Research

Abstract

DEM-FEST was a national public engagement event organised by a cohort of applied dementia researchers funded by the National Institute of Health and Care Research. Events took place across England during Dementia Action Week [19 to 25 May] and data for this report were collected from attendees, including people living with dementia, event organisers, and web analytics.

Ruth Bartlett
R.L.Bartlett@soton.ac.uk

What was the National Festival of Applied Dementia Research?

The festival was an England-wide public engagement event organised by DEM-COMM – a cohort of post-doctoral researchers working in applied dementia research, funded by the National Institute of Health and Care Research (NIHR) and Alzheimer's Society. The festival was initiated by NIHR ARC Wessex, the host and co-ordinating centre for DEM-COMM.

The festival was an opportunity for DEM-COMM researchers to mobilise knowledge in creative ways and in different places, with people concerned about or living with dementia, including family carers.

DEM-FEST 2025 took place during Dementia Action Week (19-25 May) organised by the Alzheimer's Society.

Partner Institutions

The festival was run in collaboration with the 15 NIHR Applied Research Collaborations (ARCs). These are:

- ARC South West Peninsula
- ARC Wessex
- · ARC Kent, Surrey, and Sussex
- ARC West
- ARC Oxford and Thames Valley
- ARC South London
- ARC North West London
- ARC North Thames
- ARC West Midlands
- ARC East Midlands
- ARC East of England
- ARC North West CoastARC Greater Manchester
- ARC Yorkshire and Humber
- · ARC North East and North Cumbria

Aims of the Festival

The aim of the festival was to help make life better for people concerned about or living with dementia, including family carers, by providing opportunities for people to learn about the latest developments in applied dementia research – that is work that aims to find solutions to the practical problems that people living with dementia can face.

Data gathering

Data were gathered from attendees and event organisers.

Who provided feedback received from

- 939 attendees
- 15 event organisers

Headline facts and figures

A total of 939 attendees were recorded.

Count of events taking place

There were 22 events. Each ARC ran at least one event. ARC Greater Manchester and ARC North West Coast teamed up to run a joint event. ARC Yorkshire and Humber ran three events. ARC North East and North Cumbria ran two events. ARC Northwest London ran a 5-day event.

Target audience

All events were aimed at people concerned about or living with dementia, including family carers. Two events were specifically for people from South Asian communities, and one event for people from Afro-Caribbean Communities. Seven events also targeted service providers, researchers, and health and social care professionals.

Types of events

Twenty-one events were in person. One event was online. Here is a breakdown of types of events:

- Public conversation / Q&A session/ workshop (12)
- Film screening 'Life in Embrace' (2)
- Public conference/community event (2)
- Art exhibition in-person (1) and online (1)
- Tea Dance (1)
- · Virtual reality immersive experience (1)
- Chair-based Yoga (1)
- Walking football (1)

Events were on different themes, including:

- Living with dementia
- Support needs
- Cultural experiences
- Physical activity
- Diet and nutrition
- Music and singing
- Taking part in research
- Dementia-friendly communities
- Brain health and dementia prevention
- · Understanding dementia care research.

How attendees found out about events

Attendees found out about events through:

- The NIHR ARC Wessex website, where events were advertised and a downloadable programme was made available. There were 832 views of the NIHR ARC Wessex website between March and May (the months leading up to the festival) with DEMFEST related pages having the most views for this entire period (664).
- Posters, flyers, word of mouth.
- Academic networks.
- · Eventbrite, LinkedIn, Facebook and other social media
- Hosts advertising the events
- Local South Asian Radio advertisements

Collaborators

Events were run in collaboration with other organisations and individuals, including:

Allison Smith (Prescribing Support Dietician)

Alzheimer's Society South Asian Group (Sahara)

Alzheimer's Society Stoke-on-Trent Branch Staff

Beth Johnson Foundation (Stoke-on-Trent) (Professor Sue Read).

Bournemouth Symphony Orchestra

Bright Shadow Dementia Arts Charity (Lucy Stockton-Smith and Becky Vincer), who worked with approximately 20 people living with dementia and carers to explore 'support that matters'.

Dementia Action Alliance Westminster and Kensington

Dementia Health Integration Team, Bristol Health Partners

Dementia Partnership Board, Hammersmith and Fulham

Hertfordshire County Council

Join Dementia Research

Igbo Union Yorkshire CIC

KIDWISE

Newcastle United Foundation (Thomas Graham)

Stoke-on-Trent Film Theatre

St Thomas Complex Care Home - South Shields

TOSH (The Old School House, Boscombe)

Venues

Events were hosted in community venues across England, including:

The Biscuit Factory, Reading

Blackburn Hall, Leeds

Clevedon Library, Somerset

Cloth Hall Court, Leeds

Creative Space Art Gallery, Whitstable, Kent.

Fulham Pier, London

The Living Centre, London.

The Royal Hotel, Weston -Super-Mare

Stanstead Lodge Senior Club, London

Stevenage Leisure Centre, Stevenage

Stoke-on Trent Film Theatre

Tiverton Library, Devon

New Art Exchange, Nottingham

Newcastle United FC Foundation

Plymouth Central Library

Plymouth Methodist Central Hall

The Old School House, Boscombe

Torpoint and Bodmin Library in Cornwall

Wade Conference Centre, Stoke-on-Trent

One event took place in a care home - St Thomas Complex, South Shields

What did attendees say about events?

Brain Health and Dementia workshop in the black African communities, Workshop organised by NIHR ARC Yorkshire & Humber.

- "This workshop changed my orientation about dementia that I have to make the decision to change my lifestyle"
- "I have lived in this country for more than 20 years, but I still did not realise dementia affects black people the way this workshop has informed me"
- "I learnt that dementia is a medical condition"
- "I am better aware of dementia risk factors"
- "I am surprised that loneliness and air pollution are risk factors and will make efforts to change lifestyle in this context."
- "Until today, I thought dementia was a normal ageing"

Support That Matters: A Dementia Art and Research Exhibition, Art exhibition organised by NIHR ARC Kent, Surrey Sussex.

In response to the question, 'prior to this exhibition how often did you reflect on the role or impact of arts in the lives of people with dementia' attendees said:

- 'I did not understand capability and impact at different stages of dementia'.
- 'I hadn't made the connection before'.
- 'I suppose I think about it in the context of support. My dad lives with dementia but seems to be a stage where he doesn't like to engage with activities'

In response to the question: what word or sentence captures your experiences; attendees said:

- 'I'm so grateful this exhibit is raising awareness, and helping beautiful people'
- 'Outstanding to see the creative engagement of people with dementia'
- 'Eye-opening'
- 'It will be good if more public funding can be used to support this kind of research and event as its meaningful'
- 'Pleasing but more help and support please!'

'What is happening in dementia research in the West Midlands?' Film screening organised by ARC West Midlands

• 'the portrayal of the experiences of families had captured the "reality" of living with or alongside dementia regardless of any cultural differences'

What did attendees say about events?

Community event organised by ARC South London/Dementia Community Research Network

- "Speakers were varied and interesting. Nice food + fun music. Good mix of informative talks and networking"
- "The cohesion of everyone coming together to disseminate information"
- "Having the opportunity to meet so many South London based groups involved with dementia care and research"

Dementia research in the North East – how can it help me? Workshop and walking football organised by NIHR ARC North East and North Cumbria

- people said they found (the event) really interesting and easy to understand.
- attendees commented that they would never usually find out about research and are now keen to actively take part.
- since attending the event two people living with dementia (and their wives) have started to attend the weekly dementia friendly walking football sessions

Dementia Research and Me, Interactive talks organised by NIHR ARC West

 Many people highlighted that they hadn't realised how much research was happening and were heartened to learn about this.

'What is happening in dementia research in the West Midlands?' Film screening organised by ARC West Midlands

• 'The film was very well received and had a powerful impact, generating many thoughtprovoking insights and questions. The film created a space for dementia to be seen as it is, rather than as a research topic, it effectively 'brought dementia in' (Reflection from an ARC West Midlands DEM-COMM fellow).

Dementia research in the North East – how can it help me? Workshop and walking football organised by NIHR ARC North East and North Cumbria

- It was very well attended by a range of stakeholders including people living with dementia, family carers and voluntary sector professionals. The local media also attended giving us some extra community reach! We had some lovely feedback (verbally and via email) on the topics presented which people said they found really interesting and easy to understand. Some attendees commented that they would never usually find out about research and are now keen to actively take part.
- since attending the event two people living with dementia (and their wives) have started to attend the weekly dementia friendly walking football sessions.

What did event organisers say about events?

See Dementia Differently: A journey through research and lived experience Drop-in interactive event organised by NIHR ARC North Thames

• The event was very diverse in terms of topic areas and outputs, something that the attendees seemed to appreciate a lot. The location was perfect, and it allowed for people passing by the community centre to drop in and check out the stands.

Brain Health and Dementia workshop in the black African communities, Workshop organised by NIHR ARC Yorkshire & Humber.

• 'I hope this event can be held every year to expand the impact of our applied dementia research and support people in a more direct and practical way'.

Do you want to help and improve care and support for people with memory problems and dementia but don't know where to start? Interactive workshop organised by NIHR ARC East Midlands

'Creating the video - talking with our public contributors about their involvement - how they got involved and the benefits of involvement was inspiring and is a legacy of the event - accessible online. We had good interaction with the venue and community leaders. Some people would like to see more community creative activity as part of research engagement'.

Dementia Community Research Network (DCRN) Public Conference Public Conference organised by NIHR ARC South London

• 'We welcomed over 80 people at the community conference, including people affected by dementia, health and social care professionals and charity providers. We have received feedback from our community partners who took part that they have welcomed conference attendees as news to their services and that they valued the opportunity to network with other local organisations. They also commended the choice of community venue and the opportunity to learn about different research projects. We have already started to engage our partners for next year's event'.

How do we foster dementia-friendly communities? Workshop organised by NIHR ARC East of England and Hertfordshire County Council.

'We explored questions around what makes a successful dementia-friendly community with partners from across Hertfordshire County. We focused on public awareness, environmental adaptations and better methods of information sharing. These conversations are feeding into the implementation of the Hertfordshire County dementia strategy. The success of this event led Hertfordshire Council to organise follow-up conversations in other areas of the county'.

Festival photography



Image 1: DEM-COMM fellow Dr Emmanuel S Nwofe speaking at the 'Brain Health and Dementia workshop in the black African community' organised by NIHR ARC Yorkshire and Humber.



Image 2: DEM-COMM fellow Dr Hannah Wheat engaging with an attendee at the 'Dementia Care Research: What's that all about then?" event organised by NIHR ARC South West Peninsula



Image 3: Attendees and DEM-COMM Fellows at the Dementia Community Research Network (DCRN) Public Conference organised by ARC South London



Image 4: Event organiser preparing food for the Chai and Chat: South Asian Dementia Café event organised by NIHR ARC Yorkshire and Humber



Image 5: DEM-COMM Fellow Dr Steven Lyons with Leanne (activity co-ordinator) and Jackie (home manager) at workshop event 'Connecting through music to support people living with dementia' organised by NIHR ARC North East and North Cumbria.



Image 6: DEM-COMM fellows in discussions with partner around Hertfordshire County around the question: How do we foster dementia-friendly communities? Event organised by NIHR ARC East of England and Hertfordshire County Council.



Image 7: People taking their seats for the ARC West Midlands DEM-FEST cinema event at the Stoke-on-Trent film theatre. The documentary film "Life in Embrace" premiered at the event was produced by DEM COMM Fellow Dr Subhashisa Swain.

Festival media

The workshop and walking football event organised by Dr Marie Poole NIHR ARC North East and North Cumbria was featured in Chronicle Live, a daily newspaper covering North regional news with a circulation of almost 6,000. The article including a photo was on how football clubs are helping change lives of people with dementia in the North East, written by Emily Grey, 23 May 2025.

Festival blogs

Several people have written blogs about the events they were involved in. These include:

- Connecting through music to support people living with dementia ARC Published on the NIHR ARC North East and North Cumbria website.
- <u>Capturing Public Discussion of Dementia Research</u> published on the NIHR ARC West Midlands website.
- Seeing dementia differently published on the ARC North Thames website
- Attending the Dementia Community Research Network (DCRN) conference as a person with lived experience | ARC South London
- YH ARC Researchers Share Breakthroughs During Dementia Action Week ARC
- Geeti Kabra | Health & Social Care Workforce: Dementia Community Research Network
 Annual Community Engagement Event. Published on the NIHR Policy Research Unit in
 Health and Social Care Workforce blog page at Kings College, London.

Lessons Learnt

This was the first time DEM FEST has run. We asked event organisers for feedback about their event and what (if anything) they would do differently next time. Here are the lessons learnt:

- It can be challenging to formulate an event that is appropriate, interesting to the public, enjoyable and deliverable in the time available (i.e. six months).
- More guidance is needed on planning a public event and administrative support is required.
- More support with publicising events; despite the best efforts of hosts and event organisers some events were not well attended by people living with dementia.
- Join forces with other researchers working in the field to provide a broader 'public offering'.
- Planning events with local organisations for a particular week (i.e. Dementia Action Week) can be challenging and constraining; events could be organised outside this week.

Acknowledgement

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Disclaimer

The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.