

Dear <<First Name >>,

Welcome to our Autumn newsletter!

We hope you enjoy reading about our progress. Highlights include our October dementia prevention workshop, held in Nottingham with a range of experts including those with lived experience. Tommy Pouncey, PPI advisor has written a blog of his experiences of attending. After some interesting and creative discussions among attendees with lived, academic, policy and clinical experience, we are now developing a "consensus statement", to share our perspectives on the way forward for national dementia prevention policy.

Our next major event will be in York Guildhall, on 21st January 2025. We plan a panel discussion co-organised with the University of York's 'Curiosity Partnership' and School for Social Care Research; to launch our work exploring the training needs of the health and social care workforce around dementia. You are most welcome to join us - please register [<https://www.eventbrite.com/e/the-future-dementia-workforce-tickets-1027230041707?utm-campaign=social&utm-content=attendeeshare&utm-medium=discovery&utm-term=listing&utm-source=cp&aff=ebdsshcopyurl>] to join us. We have produced the first paper from this theme; a systematic review of policy and evidence is currently available as a preprint. Read more about our progress below.

We had a great day with children and adults at a public engagement event in August, with activities and discussions around brain health at QMUL's Centre of the Cell in Whitechapel. Finally, a team of DeNPRU-QM Public Advisor Researchers have

presented at their first conference this week, read [all](#) about this and other great work from our team below!

If you would like to find out more about our work, you can follow us on Twitter ([@DeNPRU\\_QM](#)) or get in touch via e-mail ([denpru@qmul.ac.uk](mailto:denpru@qmul.ac.uk)).

[Professor Claudia Cooper](#) and [Professor Sube Banerjee](#)

Co-Directors, DeNPRU-QM

---



Dementia prevention discussions underway at the policy workshop in Nottingham. © DeNPRU-QM.

## **Dementia Prevention Policy Workshop**

On October 3rd and 4th, we welcomed experts from across England to Nottingham for a two-day workshop on dementia prevention policy. Attendees included leading figures from clinical, academic, and policy sectors, as well as representatives from major charities, those with lived experience, and early-career researchers. The primary goal was to explore how the extensive epidemiological evidence on dementia risk can be translated into actionable public health policies and inform research commissioning.

The workshop featured a dynamic mix of presentations and moderated discussions, including an insightful talk by Rosemary Phillips, co-chair of DeNPRU-QM's Patient and Public Experience Group (PPEG), who shared feedback from focus groups held with those with lived experience prior to the event.



Rosemary Phillips presenting at the dementia prevention policy workshop in Nottingham. © DeNPRU-QM.

Work is now underway on a Delphi consensus process to establish expert agreement on the key policy recommendations discussed. These will be submitted to the Department of Health and Social Care and prepared for publication in a peer-reviewed journal early next year.

---

## Lived experience reflections on our dementia prevention workshop

**Tommy Pouncey, one of our Patient and Public Experience Group members, provides his perspective on our dementia prevention workshop.**

I was nervous, I'd been talking to a mate who explained that Neurologists were the nerds of a hospital, I sat wondering if I'd have anything to say. He said "Surgeons are

rockstars and Neuros always have their nose in a book". Riding the train down to Nottingham, I could feel the apprehension, even the smelly feet of a passenger couldn't distract me. The consensus was held at hotel close to Nottingham University, as I took a taxi through the city the red sandstone buildings gave way to a modern glass building surrounded by ponds and lakes with geese mithering each other

Walking through the doors I saw Charlie and Charlotte who I knew from video calls. They were all sat having a beer, now beer I can do, with each sip the apprehension faded, they were all just lovely kind people. So many lovely and interesting people. Alison, Sedigheh, Claudia, Harriet everyone so fun to talk to. I was at ease.

The consensus started the next morning, the best neurologists of the country, government advisers, researchers, psychologists, journalists, a bonanza of boffin business. I heard stories of people flying in from Canada, other stories of VIP neurologists, this felt like a big deal, something important. Even Michael Jackson was coming, which surprised me as I thought he was dead, turns out it's numerologist of a similar name and not the pop star.

I'd love to tell you how easy it was to just sit there in the conversation, it wasn't easy at all. Hearing these people speak astutely and broadly about difficult concepts and ideas; as a layman, was incredibly difficult. Cohorts, low agency, apolipoprotein E, prodromal, pathologies. Heck, I was in a diction tumble dryer being bounced around until the next new word hit me, then the acronyms started. At times I wasn't sure if English was being spoken. I spent a lot of time on my phone googling words, I think I heard 4 words I'd never heard before. The difficulty was invigorating and exciting. I loved it.

The bit I didn't like. We sat in the cafe, adorned by bits of old bicycle tat; turns out Raleigh bikes were built in Nottingham and gluing seat posts and battered old wheels to the wall was cool. It was some of the weirdest and prissiest food I've ever eaten. Heritage carrot and quinoa salad with pomegranate... warm watermelon and pumpkin seed salad... it's was extremely healthy and super odd. Every meal seemed accompanied by another type of melon. I was melonned out my melon by the second meal.

For me, to find myself in the middle of these conversations and in the room was astounding and wonderful. After a few hours I'd caught up with the language barrier and I was chipping in. Since joining the PPEG I've struggled to see the links between chatting online and research which benefits people, yet here I am in an important conversation speaking about things that will dramatically change outlooks for thousands of people. I'm definitely doing this again.

---

# Join us in York to discuss the future dementia workforce

One focus of DeNPRU-QM is to consider how the quality of education and training of the health and social care workforce can be improved. To do this our workforce team are conducting a series of literature reviews across dementia and neurodegenerative diseases. We are delighted that our first review focused on dementia and the social care workforce is now available to read:

‘Systematic policy and evidence review to consider how dementia education and training is best delivered in the social care workforce, and how policy does or can enable its implementation in England’

<https://www.medrxiv.org/content/10.1101/2024.08.24.24312532v2>

For this review we looked at studies between 2015-2024 and found strong evidence for dementia training in care homes, but a relative lack of research in home care. Policy options identified to implement evidence require investment, which could deliver substantial savings across health and social care. The team are working on a further two dementia focused reviews, which will be available later this year.

To take this work from the page to the public stage we are holding a free panel discussion on 21st January 2025 in York in conjunction with The Curiosity Partnership and School for Social Care Research from the University of York. The discussion will cover a range of pertinent topics including, how do we support skills in the health and social care workforce; to enable the best care for those with dementia and their carers, how can we prepare for a ‘National Care Service’ and what are the best ways to take research evidence and put this into practice.

To discuss and debate these issues, we are delighted to be joined by an expert panel, which will be chaired by Prof Yvonne Birks, and include:

- Dr Zena Aldridge, Regional Clinical Lead for Dementia, NHS England
- Prof Sube Banerjee, Pro-Vice Chancellor & Professor of Dementia, University of Nottingham
- Sarah Gribbin, Head of Learning and Development, Home Instead.
- Mark Macdonald, Associate Director of Advocacy and System Change, Alzheimer’s Society
- Dr Mohammed Akhlak Rauf, Founder and Director of Meri Yaadain

There will be time afterwards over tea and coffee to further discuss the issues raised and meet members of the DeNPRU-QM team.

If you would like to be amongst the audience, please see Eventbrite for further information and to register for a free ticket:

Register here



Members of DeNRPU-QM discussing brain health with families at the Centre of the Cell, QMUL. © QMUL

## **‘Celebrating Science’: talking with children and parents about brain health**

We had a great day at the ‘Celebrating Science’ event for families at the end of August. The event was held at the Centre of the Cell, a science education centre based at QMUL, and was part of their summer programme of activities for children.

We talked about brains and brain health with children and their parents, they did brain-health themed colouring in and word searches, looked at models of brains, and took away brain-themed stickers and pencils. It was great to see how interested and engaged the children were!



Discussing brain health with families. © QMUL.

---

# Congratulations!



Congratulations to our DeNPRU-QM Public Advisor Researchers, who presented at the 6th annual Liverpool Dementia & Ageing Research Conference on the 23rd of October.

Annie Jones, Susan Williams and Emma Williams, from the University of Liverpool, presented on “How it feels to be a layman employed in an academic world: First insights from the public advisor researcher role” We look forward to hearing all about it!

Public Advisor Researchers with DeNPRU-QM, presenting at the 6th annual Liverpool Dementia & Ageing Research Conference.

© Clarissa Giebel

---

**NIHR** | Policy Research Unit  
Dementia and neurodegeneration  
Queen Mary University of London

*Copyright (C) 2024 Queen Mary University of London. All rights reserved.*

You are receiving this email because you opted in via our website.

Our mailing address is:

Queen Mary University of London Yvonne Carter Building 58 Turner Street London, London E1 2AB United Kingdom

Want to change how you receive these emails?

You can [update your preferences](#) or [unsubscribe](#)



