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# NIHR

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

Dear <<First Name>>,

Welcome to the second newsletter from DeNPRU-QM, the NIHR Policy Research Unit in Dementia and Neurodegeneration based at Queen Mary University of London.

Since our previous newsletter in March we have continued to expand the team. Work is progressing well on the **'Workforce'** project, focusing on how dementia training and education is best delivered across health and social care sectors and how this might inform future policy by improving dementia attitudes, detection and care. We held an event with managers from home care agencies in April (more information on this below) and care home workers attended a workshop in June. Dissemination plans are progressing for a panel event with the University of York's 'Curiosity Partnership' early next year.

We have received the results of our **YouGov poll** looking at public attitudes to prevention of dementia, Multiple sclerosis, and Parkinson's Disease. We will publicly share the results later this year. Recruitment is underway for memory services in England to complete a survey as part of our **National Provider Survey**, which aims to gather comprehensive data about memory services across England so that we can inform policy decisions about these services in the future.

Below we look at a few highlights and reflections on this work and introduce you to two of our researchers. At the end of the newsletter, you will find information about an event and a conference that might be of interest to you or someone in your network. 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).

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

Co-Directors, DeNPRU-QM



## Meeting with home care workers for the ‘Workforce’ project

In April we welcomed managers from Bluebird and Home Instead home care agencies, to an event planning our survey on home care services as part of our ‘Workforce’ theme. We also discussed next steps for the NIDUS carers study, which looked at how to help both family and home carers to best care for a person with dementia at home.

Dr Anita Goh from the University of Melbourne presented (pictured below). Anita presented the Promoting Independence Through Quality Care at Home (PITCH) study, from Australia’s National Ageing Research Institute. Oliver Kelsey presented a draft survey about home care, with attendees sense-checking the questionnaire being developed and making suggestions to increase the relevance of the content.



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## **National Provider Survey: memory service survey development and recruitment**

We are currently recruiting representatives from memory services across England to complete a survey looking at service structures, processes, outcomes, historical development, and future trends, as part of our National Provider Survey.

We held three workshops with memory service colleagues to develop the survey. We aim to understand national variation in service design over the last decade, with the outcomes informing more equitable future care.

We are working to recruit as many memory services in England as possible. If you have contacts that may be able to assist us in this, please contact Oliver Kelsey at [o.kelsey@qmul.ac.uk](mailto:o.kelsey@qmul.ac.uk)

## **Reflections on Public Involvement in DeNPRU-QM from PPI leads Mohammed, Rachel and Rosemary**

Not so many years ago, research was something that was done 'for' people rather than 'with' them. They – us – were passive recipients. Then things started to change. The recognition came that people with 'lived experience' – patients, their families, and the public - had plenty to offer and that this both complemented and contrasted with the vast expertise of researchers and health professionals in the field... And PPI (public patient involvement) was born!

From the outset the DeNPRU-QM team were keen to ensure that PPI was at the heart of their work, and they have provided great support in enabling the three of us PPI leads to recruit PPI volunteers from all walks of life. We have used social media to reach people who have never been involved in research before, and who are from a wide geographical, ethnic, age and social background. Some of our PPI group are living with neurological diseases such as dementia and Multiple Sclerosis (MS). Others are or have been carers. All have very different stories to tell, and together a great deal to offer.

All of us are involved in twos or threes in one or more of the of DeNPRU-QM projects, and together we meet virtually once a month for a PPI session. Here we have the opportunity to:

- discuss what is going on overall in the DeNPRU-QM work,
- to address any issues that have arisen and to talk through any concerns,
- to learn from each other from our differing lived experiences, and
- to get to know each other better so that we can work well as a team.

To make sure that everyone feels well supported in their involvement, we offer a buddy for anyone who wants it. The hope is that all those new to the research environment and those living with the various diseases which can make participation more difficult are able to take a full part. We further hope that they find it as enjoyable and rewarding as we do as PPI leads – and even come back for more!

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## **Meet DeNPRU-QM researchers**



## **Sedigheh Zabihi**

Sedi is a postdoctoral researcher at DeNPRU-QM. She uses electronic health records like primary care datasets to provide evidence that policymakers need to develop and improve care for people living with neurodegenerative diseases like dementia, MS and Parkinson's disease. She is currently looking at co-existing diseases in people living with MS, how they are managed and how they affect wellbeing and mortality. The results will provide evidence on which of these co-existing diseases should be made a priority for prevention and treatment. She is investigating if sociodemographic factors and health inequalities affect the association between the neurodegenerative disease and co-existing diseases.

## **Saskia Budgett**

Saskia is a Research Assistant in DeNPRU-QM. She is currently working on a systematic review on dementia education and training for the multidisciplinary health and care workforce study. It involves a rigorous search for training programmes and interventions that impact the knowledge and skills for diagnosis, treatment and care for people living with dementia. The review aims to explore the knowledge and skill gaps that impact the healthcare system and staff. As Disease Modifying Treatments for dementia are on the horizon, it will explore the need for additional training and understanding from health care staff.



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## **Upcoming events and opportunities**

### **Launch event of EquaDem Network**



[Book tickets here](#)

## Plus: a new national network on finding solutions to dementia inequalities

**When?** 17th July, 13.00-15.30 (Refreshments 13.00-13.30)

**Where?** University of Liverpool, Central Teaching Hub  
For whom? People with dementia, unpaid carers, health and social care professionals, Third Sector, Commissioners, anyone with an interest in dementia

**What?** Find out about what we do, who we are, how to get involved, secure a research internship or pilot funding, and how we aim to reduce inequalities.

## Now Open: abstract submission and registration for the 6th annual Liverpool Dementia & Ageing Research Conference

This year's Conference theme focuses on "Spotlight on public involvement and engagement in dementia research and care". The Conference is open to academics, students, health and social care professionals, Third Sector representatives, funders, commissioners, and people living with dementia and unpaid carers.

**Date and time:** Wednesday 23rd October, 9.00-17.00

**Venue:** The Liner Hotel, Liverpool

[Find out more](#)

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