Dementia Enquirers Newsletter (18): June 2022

Welcome to the latest edition of our newsletter! With only a few months left of our funding, we are ploughing full steam ahead with our work on dissemination and legacy. Here's just a flavour of what we are doing:

New publication

Our latest Dementia Enquirers publication, which comes from the Shrewsbury Riversiders group, asks the question "Have you had annual dementia reviews with your general practice since diagnosis?"

Although the study was of course small in scale, the findings do suggest that there are problems with the annual review system which need further exploration. Very few of the respondents had an annual review with their general practice that was in any way meaningful to them, in terms of wellbeing and future planning. George Rook, who led the project, is very hopeful that the report can lead to change, and he has sent it to key bodies such as the Royal College of GPs, NHS England, the Health Foundation and the All-Party Parliamentary Group for Dementia. George would welcome any support in making sure that this issue is actively pursued.

Influence around the world

Dementia Enquirers has caught the attention of Emily Ong, one of the Directors of the Dementia Alliance International, and also a Focus Group member of WHO Global Dementia Observatory. Emily recently tweeted:

> “We will need more of us with dementia in the driving seat of research and policy in different parts of world, including in LMICs [lower and middle income countries].”

A new book

We are writing a book about Dementia Enquirers which will be published by JKP in 2023. We are delighted to have Dr David Crepaz-Keay from the Mental Health Foundation as our advisor and critical friend for this workstream. In September David and some of our other trusted advisors will be joining the Pioneers at a residential event in London to work on the conclusions and reflections for the book.

Stirling University

This summer we are very pleased to be working with the University of Stirling to support them in integrating our DEEP-Ethics Gold Standards into their online MSc course, the largest in the world. The Pioneers started the process by delivering an online session explaining their perspectives on research ethics and processes. They then responded to issues raised on the ‘discussion board’, as the students began to integrate the Standards into their project assignments. Finally, the students fed back to the Pioneers on how the Standards had influenced their thinking.

Here is some of the feedback we have received:

> “This session was really useful for students and staff - thank you very much Pioneers. Your guidance on ethical dementia research is a fantastic tool and will be incredibly helpful for anyone designing a research project and thinking about ethics approval.” (Dr Richard Ward, Senior Lecturer in Dementia Studies)

> “Thanks to all the Pioneers who came to speak to our students. It’s definitely inspired them as they continue with their studies… and more

importantly I think you'll have encouraged them all to think about their future professional work in much more inclusive and participatory ways." (Dr Grant Gibson, Lecturer in Dementia Studies)

"The Gold Standards will be incredibly helpful in how we improve the quality of our dementia steering group in Humber and North Yorkshire. I will also share this with all members. I would love for you to present this to one of our next steering groups too if we could please." (Gemma Willingham-Storr)

Early career researchers

As part of our legacy plan, Early Career Researchers from across the UK were invited to apply for a mini-internship with the Pioneers. To keep the application and selection processes as simple and accessible as possible, they were instructed to send a two minute video, which would be viewed by a selection panel of Pioneers. The Pioneers selected seven successful projects, each of whom were given a personalised session during the summer.

Both successful and unsuccessful applicants were also invited to a master class in May 2022. This generated excellent feedback, see the following quotes:

- "I used the example written in the Gold Standards, really helpful. And I referred to the Standards in the form for the ethics committee." (Jacoba)

- "From a researcher's point of view it's not always the top priority, so having a group of Pioneers to push forward this agenda really makes the difference for the field. "(Yah Yin)

- "This has been so useful, I really appreciate you all giving your time to speak to us. And it's given me lots to think about for how I go about doing my own questionnaires and focus groups, and making sure these are enjoyable for people living with dementia to be part of :) I would love to do co-research after my PhD (the PhD thesis has to be your work." (Felicity)

- “Thank you all for giving your time to share your advice and experiences. It’s been incredibly valuable. I will particularly take confidence in challenging Ethics Panels when trying to push through more accessible documentation, as opposed to accepting the standard lengthy jargon-filled docs.” (Phil)

Other news in brief

In June, Agnes Houston and Rachael Litherland presented on Dementia Enquirers at the 35th Global Conference of Alzheimer’s Disease International.

We are talking to the Health Research Authority about potentially piloting the DEEP-Ethics Gold Standards with Research Ethics Committees.

We plan to commission a short animation which will deliver the key messages from the programme in a punchy and accessible way. Watch this space!

We are also working on a proposal for phase 2 of Dementia Enquirers. It is likely that this will focus on developing resources; delivering master classes; linking DEEP groups with researchers; DEEP-Ethics Panels; and equipping and supporting more DEEP groups to lead their own research. We welcome any ‘heads-up’ on funding opportunities.

And finally…

If you have any queries, thoughts, inspirations or anything at all, please email Rachael at rachael@myid.org.uk or call her on 01392 420076.

And don't forget you can find all the Dementia Enquirers resources here. These include a free research pack; the DEEP-Ethics Gold Standards; podcasts; webinars; short films; audio Diaries and all previous newsletters.

We look forward to talking with you all again soon ☺
Stay safe, stay strong, stay connected