Dementia Enquirers Newsletter (19): November 2022

Welcome to the latest edition of our newsletter!

Well we're now nearing the end of this programme – can you believe we've been at it for four years!! Our wonderful funder, the National Lottery Community Fund, has kindly given us an extension until the end of February 2023 – but there's still so much to be done!
Here's an update of recent happenings…

The Dementia Enquirers reports

We have now funded an amazing total of 24 mini-projects, all designed and led and delivered by DEEP groups (people with dementia). Most of these are already up on our website here. There is a very wide range of topics including:

Living with dementia alone or with a care partner
Discrimination and dementia
Having to give up driving
Dementia as an 'Invisible Disability'
Transport – hopes and fears during and after Covid
The pros and cons of living with dementia during Coronavirus
Annual General Practice Dementia Reviews

.. and much, much more! Do take a look!

The Health Research Authority (HRA)

The HRA are doing lots of work around their Research Ethics Committees (RECs). We have been talking with them about how we can help by sharing our learning from this programme. They are inviting one of our Pioneers to observe and feedback on their experience of attending a REC. They also want to make a very short Talking Heads film of one of the Pioneers for their media awareness programme. This is such great impact!

Our gathering in East London

It was wonderful to get together in early October with most of the Pioneers, and our advisors Rosie Ashworth (via Zoom) and David Crepaz-Keay, at the Royal Foundation of St Katherine, in Limehouse. We worked hard across three days – reflecting on what we have achieved in the four years of the programme, thinking about our legacy and talking about the future. We also talked about the book that we are co-producing for Jessica Kingsley Publishers (due out next year). And we had Sam Davies with us, who is making a short film that we can use at conferences and on our website. We missed Irene, Dory, Agnes and Tom – but they were certainly with us in spirit!

Wendy wrote a blog about the first day of the gathering.

Congratulations!

…to the Ecredibles who have been shortlisted as finalists in the University of Edinburgh Good Research Practice Awards in the category of 'Positive disruptor award'. Fingers crossed for the final decision in mid-November. The Ecredibles are a group of people living with dementia in Scotland, who are interested in research. They have partnered with the University of Edinburgh's ECRED (Edinburgh Centre for Research into the Experience of Dementia). ECRED offers them formal, contracted support to write research and funding bids (from Dr Katey Warran), intern support hours (from Yixuan Wang) and skills, staff support time, budget hosting and a formal partnership with a university. ECRED has awarded Knowledge Exchange Fellowships to some members. You can read their Dementia Enquirers report here.

Presentations

We gave an online-on-demand presentation at Alzheimer's Europe conference in mid-October.
And we will be showing our new film at several conferences in November – the UK Dementia Congress, the 100/6000 Conference in Dundee, and the Humber Teaching NHS Foundation Trust Annual Research Conference.
After that we'd invite YOU to show the film wherever you can! We'll let you have the link soon.

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.