



## Dementia Enquirers Newsletter (13): Nov 2020

Here is our latest news...please share with all the people who are involved in your project or work, or anyone else interested!

### New projects take off!

We are delighted to announce 5 new small projects. These will all be run by DEEP groups who feel they can get a project going even in this new world of social distancing. The groups and their topics are:

**STAND** – standing up to develop the FIFE dementia strategy

**Forget Me Nots** – how Covid has impacted connections with others, including people with dementia

**Beth Johnson Foundation** – the pros and cons of living with dementia through Coronavirus

**Budding Friends:** how Covid and lockdown has made me feel

**Thred:** Hopes and Fears for people with dementia during and after Covid

All the projects were assessed by the Pioneers, who took the opportunity to test out our [DEEP-Ethics Gold Standards](#). You can watch a [film](#) of them practicing applying the Standards to a 'dummy' project proposal. We'd like to thank Dr Lucy Series, Prof Tom Shakespeare and many others for all their help and support with this process.

## UK Dementia Congress 2020

Like everything else, this important event has been virtual this year. However, undeterred, we made and submitted a film which focuses on some of the challenges and learning from Dementia Enquirers. You can watch it [here](#). And here's some feedback:

### **Anna Park, Care & Education Consultant at OM Interactive**

*So much to take away from this. So good to see everyone working in real partnership, busting myths & forging important professional relationships as partners in the driving seat of research. Loved Agnes's 'Getting to the heart of it and aiming high', Mhari's 'I will not lead a narrowed life' & Wendy's 'Our voices setting the agenda, our voices setting the priorities, and why not?!' Fabulous stuff. You really are changing perceptions, changing the road map and removing barriers for future generations. Huge congratulations to the whole team.*

### **Rachel Thompson, Consultant admiral nurse, Lewy Body Society**

*Thanks to the Dementia Enquirers for sharing your developments and reflections on leading the way in research. Great film - lovely to hear your voices and thoughts on the process and I really look forward to hearing more about the outcomes of the projects.*

## Ethics issues

With the help of Dr Lucy Series, we made contact with Prof Michael Dunn from Oxford University – whose work revolves around research ethics. Michael kindly agreed to be interviewed by two of our Pioneers – George Rook and Mhari McLintock – about some of the myths that surround ethics and dementia. The discussion (carried out of course on Zoom!) was fascinating... and resulted in [this film](#).

As you may recall, Dr Rosie Ashworth has been working with Pioneers and advisors, on a literature review. This has been written into a paper where two of our Pioneers (Agnes and George) are lead authors. The paper is being

submitted to a journal for publication and we should have confirmation of this soon.

Meanwhile, Rosie is also in the process of doing a survey about researchers' experiences of the ethics review process (in both clinical and non-clinical research). If you or your colleagues haven't participated and would still like to share your experience of ethical review, please contact her ASAP at [rosalie.ashworth@nhs.scot](mailto:rosalie.ashworth@nhs.scot). So far, 21 dementia researchers have completed the survey and given us ideas about what works and what needs to change in the current review process. The Pioneers and advisors will work together to analyse these findings.

### Other news

We were very pleased to have an article about Dementia Enquirers published on Alzheimer Europe's website in November.

### Christmas

As one of our hugely valued allies and supporters, we'd love to invite YOU to our DEEP Christmas Celebration on Wednesday 23<sup>rd</sup> December at 15.00 (3.00 pm). There'll be poems, songs, stories, fun, friendship and solidarity. Sign up here (and/or volunteer to do something) <https://bit.ly/36FBmqI> or email Rachel at [niblock@myid.org.uk](mailto:niblock@myid.org.uk).

### And finally:

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

And don't forget you can find all the Dementia Enquirers resources at <https://www.dementiavoices.org.uk/dementia-enquirers/>. 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**

