



Dementia Enquirers Newsletter (17): March 2022

Hi everyone. We can't believe we are already in our final year! We are all learning and achieving so much together. Here's a flavour...

Influence around the world

The Dementia Enquirers programme is now becoming known around the world! Here are a couple of examples of recent influence:

The DEEP-Ethics Gold Standards have been accepted for inclusion on WHO's

The DEEP-Ethics Gold Standards for Dementia Research

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Working in real partnership (co-production)

Information that is simple, accessible

Respect and acknowledgment

Type of resource: Training/tool
Keywords: Dementia, Research, Involvement, DEEP, Ethics, Gold, Standard
Languages: English
Country: United Kingdom
Region: European Region (EUR)
Publication year: 2020
Date submitted: 01/02/2021
Average ranking: ★★★★★

ACCESS RESOURCE

Global Dementia Observatory Knowledge Exchange (GDO KE) Platform. This platform contains key resources to support the implementation of the [Global action plan on the public health response to dementia 2017-2025](#). It helps countries and

communities to respond to dementia by sharing resources, supporting mutual learning and promoting the exchange of knowledge. You can visit the Knowledge Exchange [here](#). Thanks to Pioneer Howard for enabling this.

We also received some lovely feedback from Lawrence Van den Bogaert, a Belgian researcher: "The Gold Standards were very helpful to consider some things I might otherwise have forgotten (e.g. "Offer to help with travel plans, remote access, meeting people at stations etc. if they need/want this to keep them safe"). Overall, I found it a useful list to reflect on a wide range of

relevant items. I think it is a great addition to any ethical committee submission for research projects that involve, in any way, people with dementia.”

Cohort 3 projects

On 21st March we held an update session with our current Cohort 3 projects. We were delighted that 9 groups were able to take part. It was so exciting to hear how they are getting on. Here are some examples:

- **Beth Johnson Foundation** (Stoke on Trent): investigating dementia testing. Work on the questionnaire has taken time but a good response
- **Stand** (Fife): working to influence the Fife Dementia Strategy. They will use their DEEP gathering in June to discuss a draft
- **Scottish Dementia Alumni**: their work on a physical game for school children about dementia is progressing
- **Up and Go (Leeds)**: their project on post-diagnosis opportunities is currently waiting for ethical approval
- **Forget me Not Researchers** (Bristol/Swindon): their work on post-diagnostic support has received ethics approval (it took a long time!). They will soon be running focus groups
- **Shrewsbury Riversiders**: their report on annual GP assessments (or not!) will be published very soon on our website
- **Lifting the Cloud** (Derby): they have completed their audits of local attractions and are now working on their access booklet
- **Ecredibles** (Edinburgh): currently writing proposals for two projects
- **Great Camden Minds**: looking at online exclusion (not just a rural issue)

Planning our legacy

As you may already know, funding for this phase of Dementia Enquirers finishes at the end of 2022. So, we are focusing very much on dissemination of our learning, and the legacy we can leave. Here are some current actions:

- We are **writing a book** for publisher JKP. This will describe what we have done, what we have learnt – and how we hope things will change. It will draw on the many projects and conversations we have had along the way. There will be an event for Pioneers and Advisors in September to work on the conclusions and reflections (date/venue tbc soon).
- In February, the Pioneers reviewed 20 video applications from Early Career Researchers. They selected 7, each to be offered a **mini-internship**. All 20 applicants will also be invited to a Masterclass by the Pioneers in May.
- The **University of Stirling** wants to integrate our DEEP-Ethics Gold Standards into their research, and their online MSc course (the largest in the world).
- We have made a short film to be shown in March to the **Dementia Research Funders Forum** (DRFF), which brings together government and charitable funders of dementia research.
- We are talking to the Health Research Authority about potentially piloting the DEEP-Ethics Gold Standards with Research Ethics Committees. Watch this space!

If YOU can help us with other legacy actions – or know of a funder 😊 who may be interested in supporting us in a Phase 2 – please contact us ASAP!

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

