



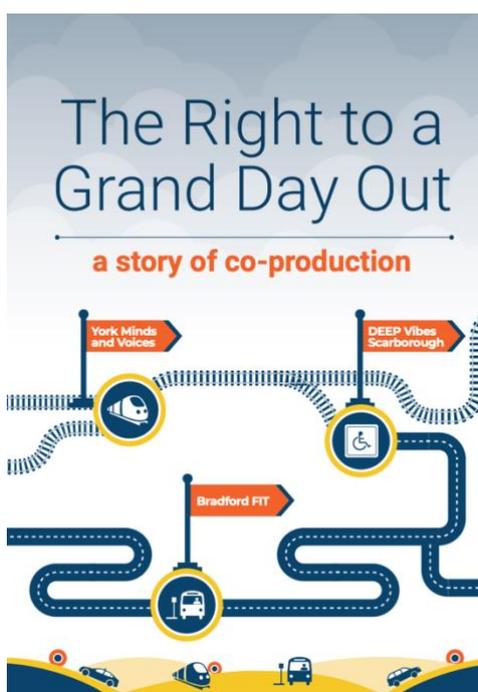
Dementia Enquirers Newsletter (12): July 2020

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

New funding

While our next cohort of projects will inevitably be delayed because of COVID-19, the Pioneers have decided to release a small amount of funding to DEEP groups who feel they can get a project going in this new world of social distancing. Our call will go out in the next few weeks.

New resources



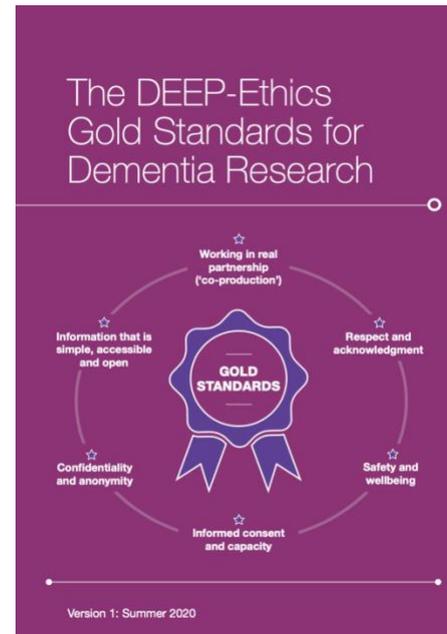
Before Dementia Enquirers, DEEP groups in Yorkshire worked together (with artists) on three transport and rights projects. '[The Right to a Grand Day Out](#)' is their story – and it tells us what they learned about co-production. Do take a look!

Ethics issues

Big thanks to everyone who has contributed their comments and ideas to our new [DEEP-Ethics Gold Standards](#). This has been a major piece of work, and we are hugely grateful to all those who have contributed their expertise and

thoughts. We will now be setting up a Sounding Board group made of people with dementia (our 'Pioneers').. We aim to pilot the Standards with our next cohort of projects. Also, if you have any projects you would like to put to the Sounding Board, please let us know. Watch this space!

Meanwhile, Dr Rosie Ashworth has been working with Pioneers and advisors, [combing the scientific literature](#). They are looking for examples of when people living with dementia have been included in research ethics review processes. Rosie now has an important request:



" We are very aware that there are often excellent examples of inclusion outside of academia that are harder to pick up in the review process. We would like to ask you if you are aware of any projects where people with dementia, or people with lived experience of other health conditions, have been [included in the ethics process](#). This would help us to strengthen the work we are doing around best practice in ethics. If so please email rosalie.ashworth@nhs.net "

Rosie is also in the process of getting Health Research Authority ethics approval to do a survey about [researchers' experiences of the ethics review process](#). This will include clinical and non-clinical research. We are hoping these experiences will help inform the great work that Dementia Enquirers are doing around ethics.

We have also been talking with Prof Jan Oyebode at Bradford University, and her PhD student Chiara De-Poli. We've discussed their current work on [Ethics hurdles in participatory research involving vulnerable groups](#). This is a side project from their main funded study on 'Co-Designing Dementia Care'. We are delighted that they have used our 6 DEEP Ethics principles to inform their work. We are also hoping to co-author a paper with Jan and Chiara.

A co-produced journal article

Prof Tom Shakespeare has been working remotely with the Pioneers over the summer to prepare an article for submission to 'Disability and Society' in September. Watch out for it in Spring 2021!

Cancellations/delays

Our project event, due to take place at St Katherine's on **Thursday 22nd October** has now been postponed again. Sorry... but hope we'll all meet up 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 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**

