



Dementia Enquirers Newsletter (15): Sep 2021

Welcome to our new Pioneers

We are delighted to welcome four new Pioneers - Steve Kennedy, Daithi Cee, Irene Donaldson and Maq Qureshi. We now have nine Pioneers in total. All are living with dementia – and each brings a wealth of experience from their lives before dementia as well as after, to help shape the programme.

Our final round of grants

The Pioneers, assisted by Philly and Rachael, met over 4 days in July, to decide which groups should be given a share of the last round of Dementia

Enquirers grants. Pioneers were sent summaries of the applications in the post in advance. We worked on 2-3 applications per meeting. This is the decision matrix we used (see left).

Application number

You can use this scale to answer the following questions:

	My score	Please explain your answer
How does the research question make you feel?		
Do you feel that people with dementia have been and will be in the driving seat?		
How appropriate are the methods the group has chosen?		
How much difference will this project make to the group, to DEEP and to the world?		
How ethical does this project feel to you?		
Any other comments		

We are not quite ready to announce the successful projects. However here are some reflections about the grant process from the 9 Pioneers who were responsible for selection:

- We gave justice to every application.
- The pace worked well, 2-3 applications per meeting. It was exhausting, but had to be so.
- We are trying to decide what the future is going to look like. This work is significant.
- There was some magic at work. Lots of hard work from us. Lots of hard work from the applicants.
- We are all speaking with knowledge.
- Impressed by the answers to the ethics questions.
- These applications were much better than Round 1 in 2019. It is much clearer that people with dementia are in the driving seat.
- The topics are great. Practical and on the ground.
- They are focusing on things that matter to people with dementia.
- The pace and control of the whole process were absolutely perfect. Whilst we had the odd joke, things needed to be moved along. I genuinely found so interesting and enjoyable. Each and every single application was given equal analysis by the group which was beautifully cross sectional across the UK and Ireland. I hopefully will get to work with you all again and what an amazing insight into what goes on behind the scenes in preparation of the projects for grant application purposes.

Recent developments

George Rook recently presented with Philly at a 'Research in Practice' conference. We focused on exploring how people living with dementia can go beyond 'patient and public involvement' and be 'in the driving seat' of research. The audience – mainly social care practitioners and commissioners, not academics – gave extremely positive feedback.



Prof Tom Shakespeare has been working with the Pioneers to co-author a paper for the journal 'Disability and Society'. Tom describes it as 'the most enjoyable one I've written in the last 30 years!' We are delighted that this has now been published – you can read it [here](#). Six Pioneers were involved and

named as authors: Teresa (Dory) Davies, Agnes Houston, Howard Gordon, Mhari McLintock, Wendy Mitchell and George Rook.



Agnes Houston also presented with Philly at a seminar about Public Involvement for NIHR Research Design Service Yorkshire and Humber.

Ethics issues

We are delighted to be partnering with Chiara de Poli from the London School of Economics and Political Science in a small project relating to the DEEP-Ethics Gold Standards. This has been funded by the National Institute for Health Research School for Social Care Research. We hope this work will contribute to a research proposal – about making real changes in the ethics system for social care research in England.

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**

