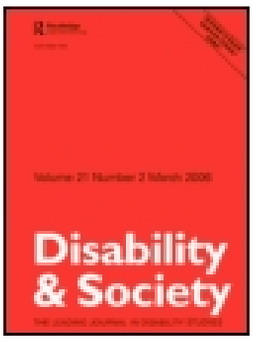

Disability & Society

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/cdso20

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To cite this article: Teresa Davies, Agnes Houston, Howard Gordon, Mhari McLintock, Wendy Mitchell, George Rook & Tom Shakespeare (2021): Dementia enquirers: pioneering approaches to dementia research in UK, Disability & Society, DOI: 10.1080/09687599.2021.1916887

To link to this article: https://doi.org/10.1080/09687599.2021.1916887

Published online: 07 Jun 2021.

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DISABILITY & SOCIETY
https://doi.org/10.1080/09687599.2021.1916887

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Dementia enquirers: pioneering approaches to dementia research in UK

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ABSTRACT

This paper explores the Dementia Enquirers approach to dementia research, and the 10 local projects which have been funded in the first wave of the programme. The paper is written by six people with dementia with expertise by experience, supported by a traditional academic with expertise by research. This co-production enables the voices of people with dementia to be heard, and expands the field of disability studies. The authors discuss problems with traditional academic research, and the different ways that people with dementia go about research. Two examples of research projects led by people with dementia are discussed. The paper explores difficulties people with dementia have had with formal research ethics procedures and how they propose to do things differently. In conclusion, the authors challenge mainstream dementia research to do things differently, and to understand the potential contributions of people with dementia.

ARTICLE HISTORY
Received 3 September 2020
Accepted 10 April 2021

KEYWORDS
Dementia; co-production; research; ethics; advocacy

Points of interest

- People with dementia can conduct research
- People with dementia understand ethics and can come to considered judgements about capacity, consent and the risk of harm.
- People with dementia may sometimes enjoy advantages in their ways of working
- Mainstream research and research governance needs to adapt, if people with dementia are to be included.

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Introduction

> Whether we call it research or not I really don't know but that will be up to the professionals to decide on that. (Agnes)

In the disability field, it is increasingly the case that people who use services have control over the research process, rather than professionals (Staley 2009; SCIE 2013). People with physical and sensory impairments (Barnes 2003), people with learning difficulties (Boxall, Carson, and Docherty 2004; Tuffrey-Wijne and Butler 2009), and people with mental health conditions (Slay and Stephens 2013; Rose 2017) have all been involved in what is variously called co-production, patient and public involvement, or emancipatory research (SCIE 2013; Williams et al. 2020).

This rights-based approach is relatively new in the dementia world (Eley 2016; Shakespeare, Zeilig, and Mittler 2019). Dementia is not always seen as a disability: disability rights has not always included people with dementia (Mental Health Foundation 2015; Shakespeare, Zeilig, and Mittler 2019). It is rare that people with dementia lead their own research projects, or even take an active part in data collection or analysis (Bethell et al. 2018). But a rights-based, co-production approach, represented by DEEP – the UK Network of Dementia Voices, which is hosted by Innovations in Dementia (Berry et al. 2020) – is growing rapidly and now comprises over 100 involvement groups of people with dementia. DEEP offers a new approach to dementia research.

The aim of the Dementia Enquirers programme (funded by National Lottery Community Fund October 2018–March 2022), is to develop this new approach. Many DEEP groups have already been involved in university research studies. However, the Dementia Enquirers programme will give people with dementia a chance to lead their own research, on issues that are important to them. The word 'Enquiry' has been used because it is less intimidating to many than the word 'Research'. People with dementia will explore how knowledge is acquired and applied in a way that feels relevant to their own lives.

This article asks can people with dementia lead research projects? What are the barriers to people with dementia leading research? What are the benefits of people with dementia leading research? We share the perspectives of people with dementia about these questions, building on previous research (SDWG [Research Sub-Group] 2014; Stevenson and Taylor 2019). Following the principle of 'Nothing about us, without us', the paper features the contributions of six authors with dementia, supported by a seventh author, a disability studies academic who has not been diagnosed with dementia. The authors are all Dementia Pioneers, who are the group helping to shape the Dementia Enquirers programme. This paper describes how the Dementia Pioneers work together nationally. We talk about how people with dementia have been excluded from research. We describe the local research projects

which have been funded under the Dementia Enquirers programme, before discussing new forms of ethical governance. Finally, we discuss the implications of this approach to dementia research.

Are the Dementia Pioneers typical of people with dementia? We are a group of white British people, who come from a range of occupational backgrounds, mainly professional, and who were diagnosed with dementia between three and six years ago. Because we have been involved in the Dementia Engagement and Empowerment network (DEEP), we have become activists for our wider community. Teresa is a retired landscape gardener, diagnosed with Alzheimer's when 59. Wendy was diagnosed with early onset Alzheimer's in 2014. She took early retirement from her work in the NHS to enjoy life 'while I'm still me'. She writes a popular blog. Mhari describes herself as a mother, a wife, a friend, an advocate for Dementia Inclusive Churches, and as someone who likes dancing, riding her tandem, and meeting colleagues on Zoom. George is a retired teacher and accountant, diagnosed with mixed dementia in 2014. He has become an activist for better dementia care, and, recently, a dementia craftivist. Agnes was trained as a Queen Alexandra Army Nurse. When she was diagnosed with Alzheimer's in 2006, she became a dementia activist. Howard was an Auxiliary Nurse in the NHS until his diagnosis of Alzheimer's and Frontal Temporal Dementia in 2017, and is now a dementia activist.

The experience of the DEEP Network and the Dementia Enquirers research programme has been transformative. Mhari explained 'It's the only place that somebody listened. Very often, people can treat you like a child, as if you can't do anything at all. We are completely written off. I was getting a bit… not quite angry but could have been. .It's good to be part of something which can challenge us, as well as them. DEEP is the best thing that I've come across… It's really changed my life, actually'. All of the Pioneers have a sense that this project is a contribution to change, as Teresa said: 'I do it to try and help for the future. For us as well now, but also for the people in the future, to try and help the researchers understand what's it's like'.

How we worked together

This is a co-authored paper, led by people with dementia at all times, in which all participants had an equal say, and where no one was in charge. It is not research conducted by an academic with, let alone on, people with dementia. For this reason, it was felt by the group to be inappropriate to apply for research ethics clearance. The co-author without dementia had worked with the Pioneers since the Dementia Enquirers funding was awarded, as one of their academic advisors, alongside Rosie Ashworth, David Crepaz-Keay, Dawn Brooker and Lucy Series. After three meetings, there was a good rapport. Tom Shakespeare offered to collaborate when they were looking for someone to help write this article. The Pioneers chose

him, as they knew him and trusted him. The role of the supporter is summed up by Agnes, talking about her collaboration with another supporter, Philly from Innovations in Dementia: 'you are so good at listening to this long-winded stuff and getting the pertinent points I wanted to say and then and saying it concisely so that others understood what it was I wanted to say'.

The working method was that meetings were held during Coronavirus lockdown, on Zoom. Tom facilitated the discussions, recorded the conversation and also took notes. As people talked, he was able to insert their contributions into the developing text. Wherever possible he used their words and phrases, both as direct quotations, but also as the connecting text woven into the narrative of the paper. Then at the next meeting, he shared the draft with the group, so that others could see what they had said, and make changes. He also had separate Zoom discussions with two of the local DEEP groups who were doing research projects.

Tom was committed to listening to the group. For example, he had suggested putting the quotations from people with dementia in italics. But then it was pointed out to him that people with dementia found italics much harder to read. Agnes told him to 'put a wee note to explain why you didn't use the normal approach', using the italic example. The listening, sharing, and checking ensured that it was truly co-production. The resulting paper is unusual in including long quotations from authors. This has been Tom facilitating people with dementia to speak for themselves, as researchers, not as research participants. Everything has been checked, modified and approved by all the authors.

The way that the Dementia Pioneers and the local DEEP groups go about their work is different from conventional academic practice. It is as convivial as it is intellectual. Mhari said everybody gains as a result, finding out about each other so that they know how to support each other: 'Because we have chatted, people know each other, you look out for each other… which is brilliant'. The commitment to hearing everyone's voice is very helpful. It's about being a team, as George said: 'The more ideas you get, the more ways of looking at a problem, the more you explore it, the deeper you get, and it becomes a really worthwhile project, you can make sure you aren't going up the wrong alley'.

Collaboration is central, but always led by people with dementia. DEEP etiquette is followed. People with dementia may forget what they are saying. So everyone has a card to show when they need to speak. If they can make their comment immediately, they are less likely to forget it. Often, a speaker will give way to someone else who may be more forgetful and therefore need to speak immediately. Sometimes, a speaker loses his way and tails off. The group are respectful of that. They give the individual time to regain his thread, or come back to him when he remembers what he wanted to

say. The online collaborative meetings finish after about 90 min, because people cannot concentrate for longer and need a break.

Pioneers were using the Zoom social media tool before the Coronavirus lockdown made it vital. Agnes explained how this was due to the influence of Kate Swaffer, a real pioneer of dementia activism, and Dementia Alliance International (DAI), a global user-led group which Agnes had joined about eight years ago: 'I learned from them about Zoom, and I had never heard of it. I then started asking professionals to do it, and they were very uncertain about it, and now I am sniggering and quietly gloating'. As Agnes explained after a previous meeting: '[it] was held with Zoom and we were all over the UK. We don't need to travel, we are sitting in our various living rooms'. Mhari said how she got 'loads of brownie points' from her friends, when they realised she was already very comfortable with Zoom. Using Zoom, Howard had been able to set up an online memory café. One of the care homes in his area was now joining in, and he had organised speakers such as a local councillor, or someone from Alzheimer's Society, or sessions of 'chairobics'. At other times, Howard played music or led reminiscence sessions.

The reliance on Zoom was very helpful at the time of the Coronavirus pandemic. Zoom was good for collaboration across the dementia activism networks and for gaining research participants. As Wendy pointed out, other research projects were coming to an end, but the Dementia Enquirers research was carrying on, with interviews being done on Zoom: 'it doesn't have to stop, there could be far more uses for Zoom than [people] realise'. Agnes said: 'I have great admiration for people with dementia, they say we can't do things, but I have seen people with dementia work outside the box, find solutions, share their solutions so others can do it, always in the driving seat. This pandemic has shown people with dementia show what they are capable of. But we are happy to ask for help when it is necessary'. The emphasis on Zoom was typical of the way that people with dementia were always having to find their own solutions. As Wendy said: 'when we meet professionals, we come out with a downward feeling for what they are saying to us. We're often asked to fill out the Mini Mental State bit, and immediately we feel a failure, it makes you feel you've failed. We would never do that'. By contrast, the DEEP network 'gives us a positive feeling, and if we can't do it, we look to each other for solutions'.

Everyone agreed when George said that people benefit hugely from working together, as individuals, in terms of support and having fun. But as he added, 'the research must gain from people working as a team on it'. The outcome is better as a result of genuine collaboration. This less competitive approach was contrasted with conventional academic life, as Agnes highlighted: 'People with dementia are very honest with one another. We are not precious with our ideas, and the help we give one another. There's

no competition. What I see in academia, working with many different centres, is 'hush hush' and 'don't tell', and everyone's precious with it, and secret'.

Wendy agreed with Agnes: 'We also create a safe environment for everybody, an environment of trust with one and other, and there's no hierarchy, and we're all entitled to our opinions. Yes, we might disagree, but it's the way we disagree. We rise above our differences to get an outcome'. She had experienced being sat in a room with academics, which could make you sometimes feel stupid, mainly because of the language that was used, that lay people could not understand or get a grasp of. 'We don't have that', she said.

The result, although apparently time-consuming, turned out to be very efficient. Short, intense days of interaction produced good results. The Dementia Pioneers found the work very exhausting, but were proud of what had been achieved: 'it would have taken others many months and many more meetings to achieve what we achieved today'.

Some of the sense of urgency behind the work was a result of the feeling that many had that they were going to lose their cognitive capacities at some future point, so they wanted to get ahead now.

Although the meetings were informal and fun, the Pioneers did not lose sight of the fact that they were trying to be more professional. They wanted to be able to break some academic rules, but they were willing to play by others, such as those governing this journal article. Ultimately, they were keen for people to read what they had to say, so that it might lead to changed perceptions of people with dementia by academics and clinicians. As Howard said: 'Too often we're getting a diagnosis and told we're incapable, but we're turning around and saying: "we are capable, and we can do the things that academics can do"'.

Exclusion from research

Several of the Dementia Pioneers had prior experience of being excluded from research. For example, Agnes explained how the Scottish Dementia Alumni group had wanted to do a project on self-management: 'But because we didn't have the backup of any influential university or research area, it wasn't as easy. And we in the group, although we had a lot of information about research, we didn't have what it took, really to get this done in a research way'. The group had wanted to lead the research project, but to work in collaboration with Edinburgh University. However, they could not get funding. Agnes felt that this was because people with dementia were leading the research. This made Agnes annoyed, and so she was delighted when Philly Hare later asked her to be part of the Dementia Enquirers project. Agnes felt that it was time that the professionals and academia started seeing people with dementia as having collective expertise, even being authors of papers: 'not just as participants, but in our own right'.

Often, people had experienced tokenism, as Teresa said: 'I've done work with researchers. A couple of them, I've been made to feel just a tick box. Just so they could say they've had someone with dementia involved. I've given my time and then heard nothing, no feedback or anything'. Wendy told the story of when she had been emailed by a researcher asking her to be on a steering committee: 'I emailed back asked for more information, how much time would it take, would I be paid and everything. She replied: "you don't have to do anything, I just want your name on the paper to get funding"'. So I wrote back, showing her the error of her ways'. As Agnes said: 'We don't do tick boxes'.

At other times, people had been victims of paternalism, in the name of ethics. Wendy talked about when she had first started to be involved in research, 'as a participant and as what I thought was an equal'. But the biggest barrier to being a participant was the researchers' insistence that her daughters were there with her. She couldn't take part in research without them. She felt this showed she had not been seen as an individual, as if dementia was her 'master status' (Hughes 1945). Later, she had wanted to take part in a project about dementia and sleep. This time, she wasn't allowed because she lived alone: 'they seemed to have one blanket rule'. Another time, she co-wrote a paper with a researcher. The person without dementia had her name on the paper, but not Wendy, because as a person with dementia, it would 'expose my vulnerability'. Rules intended to protect people with dementia, in practice excluded them.

Bureaucracy was a related problem with research ethics. George talked about having to fill in forms before he took part in research. The wad of papers was several centimetres thick: 'it just made my heart sink, and I couldn't remember half the stuff they wanted to know. If we are leading a research project, we can make sure that sort of counter-productive method is avoided'.

George believed that academic researchers came up with the topics of research before asking people with dementia to participate 'it's looking at something they've thought of, rather than something we've thought of'. By contrast, the Dementia Enquirers programme meant 'focusing on things that happen to us'. Academic research tended to be very obscure, and to keep a distance from reality. Howard pointed out how 'when we do take part in the research, we never hear any more'.

The Dementia Enquirers programme

This Dementia Enquirers programme was about 'seeing research from the inside out, rather than the outside in, and that was so different from what happened before', as Wendy said. By putting people with dementia in the driving seat of research, they could decide for themselves what mattered

to them. This message was reinforced by the Dementia Enquirers' graphic of a car pulling a caravan, courtesy of Tony Husband.

Academics have been involved in the Dementia Enquirers programme. However, this has only been as advisors. Academics have also been involved in individual Dementia Enquirers research projects, but again, only as advisors. Academics have helped with methodological questions, and sometimes obtaining ethical clearance, where relevant. A very clear and concise guide to research has been drawn up for the network by Rosalie Ashworth. To use a common disability rights movement expression, experts have been 'on tap but not on top'.

The Dementia Enquirers programme had been led by the Pioneers, on behalf of the DEEP network. As Wendy said: 'our Pioneer group met last week in Birmingham… It was an exciting time because we had put out a call for groups all around the United Kingdom to see if they had any research projects that they thought needed a little bit of grant, and they could do that would make a difference, influence and challenge the way dementia research is carried out. So with fun, with laughter, and a lot of work, we managed to pick out the people who are going to get this grant'.

Ten projects were funded in the first year of the programme, kicking off in September 2019:

Thred in Liverpool: Urban and rural transport systems.

Our Voice Matters in Hartlepool: Groups.

Shindig in Sheffield: Having to give up driving.

DEEPNess on the Isle of Lewis: Alexa videos.

Minds & Voices in York: Living with dementia with or without a care partner.

Beth Johnson Foundation in Stoke-on-Trent: Does class, intellect or ethnicity have an impact on the dementia pathway for the person with dementia?

Riversiders in Shrewsbury (with Minds & Voices, York): What do DEEP group members and Admiral Nurses know about each other?

SUNshiners in Kent: Dementia as an 'Invisible Disability'.

Memorybilia in Kent: The impact of teaching social workers about dementia at the local University.

EDUCATE in Stockport: Benefits of using Alexa.

All these ideas were from the grassroots, lived experience of people with dementia themselves, who had come up with questions or concerns. Often, there were shared interests in different parts of the country, such in the Alexa voice-activated system as an enabling technology. In these cases, representatives of the groups have visited each other to compare experiences.

The plan is for the findings from each individual group to inform the whole network. These are model projects, and it is the broader lessons learned, as well as the particular findings, which are most important. Above all, the hope underlying the Dementia Enquirers programme is that the project can influence mainstream research, while bringing new respect for the skills, expertise and resilience of those who are living with dementia.

We want to discuss two of the local Dementia Enquirers projects in more depth, to show how people with dementia are going about research.

a. 'Living with dementia, with or without a care partner' (York Minds and Voices)

This project originated from a conversation within York Minds and Voices (a local DEEP group). One individual had said that they couldn't survive without their wife. Wendy had replied that by contrast, she couldn't imagine living with anybody, because they would move things and she would not know where items had gone. From here, the study developed. It was slow to organise, because the DEEP group meet once a month, and the research project was discussed for a section of the meeting.

The research project was very much a collective effort, with Paul and Brian also contributing. For example, Brian and Damian (the group facilitator) did the literature review together. A lot of the abstracts they located were very obscure and full of jargon. But Brian said 'I'm not intelligent but I know what's what and what's not'. They discovered there was not much research on the topic, and ended up reviewing seven articles, extracting relevant points. The literature tended be more about people living with partners, and dominated by the caregiver perspective. A lot depended on the circumstances in which people were living alone: for example, new widow/ers. As Damian said 'we know that there are particular needs'.

Everyone discussed and agreed on what should be done. Damian had some ideas about methodology, which were agreed on a bus journey back from Nottingham, and he then drew up the questions. The Dementia Enquirers research pack was very helpful. Damian and Wendy looked at instructions for doing research and came up with a good set of guidelines: for example, being consistent with questions, not asking leading questions, recording and transcribing the interviews. Wendy said she found it all fascinating and that "it got the group to think of the subject. We're used to researchers queueing up to talk to us. But this got people thinking. We are more competent than people think".

Stuart drew up the consent form, being good at the precise wording. The original plan was to go through ethics at University of Hull, and they had assistance from a clinical psychology professional. However, this process proved to be laborious. The group did not want a professional even in nominal control of the research. They found there was too much paperwork

to complete. It was confusing and the forms did not feel appropriate. Meanwhile time was ticking away, so it was decided to put the formal ethics process on hold. However, the benefit of the process was that a valid consent form and information sheet was now available.

The questions were very open, exploring both the advantages and challenges of living alone and together. The versions were different for those who lived alone, and those who lived together, but investigated the same questions. For example, people who lived alone were asked to think about a situation in which someone came to live with them, and the benefits and difficulties that might arise; people who lived together were asked about the pros and cons of living alone. In each case, respondents were asked what help they might need.

Teresa was asked to act as the pilot interviewee, and this led to improvements. The study is ongoing at the time of writing. Transcription would be undertaken by the team. A researcher – perhaps a student – might be brought into help with data analysis, which could give the findings more credence.

The way the group would use the results would depend on what the results were. But the assumption was that the findings would benefit memory clinics and the social care network. People often worry when individuals live alone, so the findings might reassure those who think solitary people are inevitably vulnerable. For couples, the results might encourage services to consider relationships and offer support for people to cope as couples. But there was confidence that group members could 'tell the story', which would help 'make sure we've got it all clear in our heads'.

b. 'What do DEEP group members and Admiral Nurses know about each other?' (Shrewsbury Riversiders, and York Minds and Voices)

The idea for this project came to George and Damian during a Dementia UK meeting early in 2019, when there was discussion of getting more Admiral Nurses for dementia care. Admiral Nurses are nurse specialists, available through Dementia UK, who give expert practical emotional care and support to people with dementia. George and Damian had the simple idea of investigating how much awareness there was among DEEP groups about Admiral Nurses, and correspondingly, how much awareness there was among Admiral Nurses about the DEEP network. The research project was related to Action Research, in that it was part investigation, and part awareness raising.

A team from the Shrewsbury Riversiders group met a team from York Minds and Voices in Stockport, which appeared to be equidistant between the two regions. This meeting tested the questions for the simple survey which George had drawn up. At this point, he realised there was a need to rewrite some of the questions. The final survey had a small number of questions, plus free text boxes for further responses. The survey was also

tested by a group of Admiral Nurses in Birmingham. It went through Dementia UK as well. The research did not seek formal ethics approval, because it was thought to be about service improvement rather than academic research, and this judgement was agreed by the team at Innovations in Dementia. However, the same information about consent and anonymity and use of data that might be included on a project information sheet was included in the invitation to Admiral Nurses to participate.

Finally, the Survey Monkey online version was sent out to Admiral Nurses by Dementia UK in January and February 2020. A total of 35 responses were received. Then the survey was sent out to DEEP groups in bundles. George had to separate out the question of whether responders were aware of Admiral Nurses, and then the subsequent questions of what they thought of the services Admiral Nurses offered – these were summarised on a flyer produced by Dementia UK. There was also a separate consent form, which could be completed and detached from the main survey. The Covid-19 lockdown had prevented all the DEEP groups considering these questions. Once the survey responses were complete, George and Clive were going to analyse the findings. The report would be shared with Dementia UK, and with the DEEP network. Blogs would be produced. Possibly there would be a piece in an academic journal.

George expressed the worry that this research was very much his idea, and he had done a lot of the legwork. However, Clive did not share this concern: he felt others had been involved, it had been discussed by a wider group at every stage, and he was content that the process was being driven by George.

Ethical governance

Conventional ethical governance has made several mistakes when it comes to people with dementia (Fletcher 2020; Houston et al. 2020). For example, not all people with dementia are the same. Blanket restrictions are dangerously exclusionary, as Wendy said: 'I just think ethics should acknowledge that dementia has so many stages and people with dementia have so many individual capabilities that they need to acknowledge that, and not restrict research by only considering dementia as one group of people'.

There was a tendency to overprotect people with dementia, as Mhari pointed out: 'We're still people, we still should have things that are important, given parity for doing different things, whereas actually people just write us off, time and time again, and think they are doing us a favour. I had a thing to do with research, and that whole rigmarole, "are you really sure that's okay, that's what you want to do"'. She objected to these patronising views. She wanted to ensure that 'people are listening and not just seeing us as these poor people'.

Howard and Agnes, in line with the Convention on the Rights of Persons with Disability, also objected to the overprotection. As Agnes said: 'We do

have a right to take a risk. Not all risk is going to be detrimental to you'. Howard added: 'We have the right to make mistakes, even if they have negative consequences. One of my issues is that we are asked to take part in research, and we give informed consent while we still have capacity, and then if we lose capacity, we can't take part anymore, although we've made an informed choice. There's some research that we could continue doing'.

Because of the requirements of the Mental Capacity Act, researchers had continually to check the capacity of their contributors (Fletcher 2020). This could be very tiresome, as Agnes pointed out: 'I've been involved in research. Every time they come and see me, they go through the same thing again. You could speak to me in the morning, and then in the afternoon, and think I haven't got capacity to participate. It's a very, very, delicate situation, that I think has to be more flexible'. Wendy said that she had written it into her Lasting Power of Attorney that even when she lost capacity, her daughters know that she would still want to participate in research, so they can give that permission. There was agreement among the group that ongoing consent rather than repeated tests of capacity was best, in line with the literature (Thorogood et al. 2018).

But Howard pointed out that Lasting Powers of Attorneys (LPAs) and Advance Directives and Do Not Attempt Resuscitation (DNR/DNAR) notices could all be overridden: 'There's no guarantee that advance directives are going to be respected in future. Doctors know we haven't got capacity and do what they think is in our best interests. Agnes felt that the pandemic could lead to be more clarity on advance decision making: "I think one of the silver linings of this pandemic, is that we will have more clarity, they won't be able to fudge it, it will be very clear when you sign a DNR what it means. It's a very sad situation for many, but it will do a power of good for the rest of us."

Agnes felt that, unlike much research, they were lucky not to be under pressure, and not to have managers overseeing their work, and not to have to follow a strict protocol and guidelines. Being part of a research project had opened her eyes to the restrictions and constraints researchers are under. Research was not as simple as she had first thought: "I can now appreciate that a lot of things that happened to me, it was because of the rules of the academic world, it wasn't the researchers or the university, it was the rules that all researchers are under." Working with academic colleagues enabled her to understand the pressures that academic researchers were under, for example to get through an ethics committee. They have to see dementia through the eyes of people with dementia, and people with dementia have to look through the eyes of researchers'.

Agnes also knew why ethical frameworks were necessary: 'I know it's protection for us vulnerable people who can't do anything, I know that. Not everyone with dementia has the capacity to put researchers in their place, they can't say yes and no like us'. The first tranche of Dementia Enquirers

projects did abide by ethical guidelines: 'We followed the rules and regulations to the best of our ability'.

As Wendy said, the Pioneers cut out much of the jargon and confusion from research governance: 'we are stripping it down to basics. We wrote a booklet on how to do the research. Some academics have said how useful it is, for them'. This stripped-down guide, DEEP-Ethics Gold Standards for Dementia Research, has been prepared for the benefit of researchers with dementia and without dementia, and people with dementia (DEEP 2020). It highlights six principles:

- Working in real partnership;
- Respect and acknowlegement;
- Safety and well-being;
- Informed consent and capacity;
- Confidentiality and anonymity;
- Information that is simple, accessible and open.

George explained how the Pioneers were establishing a DEEP ethics panel for research on dementia, with support and guidance from the chosen professionals who shared the DEEP values and aims: 'We want to show that we can handle the ethical issues and approvals and the sort of research that dementia enquiries will carry out, and we want to be able to carry out guidance for the research professionals about including people living with dementia in their research both as participants and researchers'. He added: 'We want to take back control of our research and our lives, and we need to get it done'. After the first 2020 Coronavirus lockdown, Innovations in Dementia developed this alternative Sounding Board, which discussed the ethical aspects of the second tranche of DEEP projects that were selected and awarded funding. As Agnes said, we were 'our own ethics panel, to review the applications, to follow the same as professionals were doing. I think it's exciting'. With the new DEEP-Ethics Gold Standards for Dementia Research, and with the Dementia Sounding Board, Dementia Pioneers are demonstrating that they can agree rules and follow rules to ensure that research is done properly and respecting individuals. At the same time, ethics committees need to improve their procedures for service user-led research.

Discussion

In the Zoom discussion after this article was drafted, George said: 'My instinct tells me, that there's a need to draw out the themes or conclusions that we want people to get from this article'. First, George expressed the goals succinctly: 'Why do we do it as Pioneers, why are we leading this work? That's about wanting change in the way research is carried out, and wanting change

in the focus of research, so it's what matters to us'. But it was also about challenging social prejudice about dementia: 'one of the reasons that researchers at the moment think we can't do anything but play a passive role, is because they think that people with a diagnosis are incapable of doing anything. It is a disease that progresses from nothing to everything, but it may take 20, 30, 40 years for that. How many of us have met a GP who thinks that dementia means you can't do anything? We want to challenge that'.

Part of this project was about proving that people with dementia are capable, as Wendy said: 'We are doing it simply to show that we can. We still do have intellect. We can still question methods… the fact that we're reaching out to yourself, Tom, and the other academics. That creates the win: win situation. Using your academic experience, and our expertise by experience, then that's the winning formula'.

But there were also personal motivations, as Mhari highlighted: 'I'm doing it for a number of reasons: one to keep me going, to try my best to do, it's good for the brain anyway, it gives me a reason for getting up in the morning, it enables me to gain from just being around different people and finding out and making new friends and whatever, and because it's good for everyone, I do care about everyone else. It's about keeping things going and making a difference is what we're trying to do'. This could be about legacy, as Agnes explains: 'I wanted to leave a legacy for others who get a diagnosis of dementia. I also wanted to be in the drivers' seat. I was tired of constantly being asked along, to be involved in research, and putting my all into the subject, and causing brain ache, and having to rest, and being left at the end post, and not being recognised…'.

Often, the Dementia Enquirers projects were as much to do with Action Research as traditional research. Wendy felt: 'We're being questioned about whether it's research, because some researchers are feeling threatened, as if we're questioning their expertise. But we're not. We're redefining the broadness of research. We're actually researching what we want to, what we think is important'. Several of the Pioneers were concerned that their questions were too practical to be genuine research. George said: 'I think academic researchers might regard what we do, certainly in this Pioneer project, as not really doing research. It's finding out some stuff, but research sounds as if it ought to be more difficult, more obscure and abstract. But we need to make the point that just finding out how much Admiral Nurses know about DEEP and how much DEEP know about Academic Nurses is research. There are many different types of research'. Agnes agreed: 'I've been involved in professional research, very obscure questions. And I've thought what difference will this make to people with dementia? And for me, this is important research which is going to make a difference'. There was agreement that Dementia Enquirers might be about putting new questions on the research agenda, and piloting new ways of answering those questions.

But it might be down to University researchers to pick up on those questions, do bigger studies, and develop trials which were beyond the possibilities of lay researchers, whether or not they had dementia.

A third question was about how representative these authors are of the wider community of people with dementia. They are mainly from a professional background, and in early stages of dementia. All the group had experience of being told that they 'didn't really have dementia'. Sometimes, it was when they were rejected as potential participants in research studies, as Teresa had found: 'At one university, they said, 'oh well, we mostly deal with people who are further along in their dementias'… but I said, 'but that'll be me one day'. By doing the research now, while we're able, it will help for when we're further along'. Dementia involves many different symptoms, and not all people have a particular symptom, just as with other complex diseases such as cancer. Agnes said: 'We are what we are, at whatever stage of our dementia, and it's up to the researchers to find the people they need for whatever aspect of their research'. Clearly, the arguments in this article apply particularly to people in early stage of dementia, and less to people who have lost capacity and are in end stages of dementia. But Wendy said: 'it's as though researchers want their cake and eat it sometimes. They can't research in nursing homes because it's so difficult and it takes so long. Yet they question our early stages, our diagnosis. Yes, we know it's difficult to research people in care homes, in nursing homes, but it's not impossible. It's taking that whole, it's taking the whole breadth of dementia, not just these certain pockets. We're showing how dementia is much bigger than that'.

Fourth, is the key question of what the group wanted academic researchers to know. For example, the group agreed that they wanted researchers and clinicians to understand the variety of dementia experiences. They also wanted to dispel fear and stigma surrounding the diagnosis, so that people understood that folk with dementia could still do a lot of things they could always do. Dementia did not automatically mean being incapable, as Howard pointed out. The onus in research governance should be on justifying exclusion rather than justifying inclusion (Fletcher 2020). But participation was tiring for people with dementia, as Wendy said: 'People only see us for short snaps of time. They don't see the amount of work we've done to prepare for that short amount of time. So we seem eloquent, we seem capable, we seem like we don't have dementia, because of the amount of effort we've gone to, to prepare for that time. So that's why so many people question where we're at with dementia, because they don't see the times when we're stumbling… and finding it hard'.

Another point is that involvement cannot simply be a tick box exercise. George said 'For me, the problem is that they don't stand in our shoes before starting. They don't find out from us what exactly does the world look at from our point of view, through our eyes, and what matters to us'. Proper involvement work takes time. For many researchers, it might be easier not to. George

said: 'This is one of the reasons why so much consultation is so poor. It is legally forced on them. They don't understand how to do it. They say they haven't got time, 'it's not worth it, I know what I want to do, let's just get on and do it'. It's a lot about the perception that it's impossible because we have got dementia. And it's going to cost more and so on. There may be some truth in that. But morally and ethically that shouldn't alter their practice'.

Teresa said: 'When I've questioned something, they've said: but that's how we do it. That's how we've always done it. That's how we're told to do it'. Mhari complained that 'sometimes you aren't even given a cup of tea!' when people are bringing you into consultation exercises. Wendy agreed: 'We are trying to turn the priorities around. Researchers say how long everything is. But they don't spend time on the important aspect of involving us. We don't have the luxury of time. But we want to do the important things properly. We want to be able to take our time in things like this'. This means creating a safe environment – with refreshments, toilet breaks and less urgency. It has to be a good experience for both sides.

Core principles for participative dementia research are already available (SDWG [Research Sub-Group] 2014). Everyone agreed that the Alzheimer's Society dementia toolkit (Alzheimer's Society n.d.) was an excellent resource for researchers wanting to work with people with dementia. When Teresa stressed 'I think if they used more plain language, and not all the academic language, it would make it easier, for us to understand as well', this chimes with findings by Waite, Poland, and Charlesworth (2019). It was important to everyone that researchers shared the outcomes and impacts of research.

Howard explained how at Sheffield University, through the Advisory Committee with which he is involved, researchers have to come to report as part of PPI (patient and public involvement): 'they have to do a plain English presentation, and we have to give feedback on that, and our input helps determine that they get funding in the end'. Howard felt it was about being partners in research: 'For researchers to ask us what we want researched, and not decide for us what they are going to research for us. There's this perception that we can't choose the research, when we're the best people to ask in the first place'.

Wendy felt the Dementia Enquirers project demonstrated 'that there is another way. To be more open to not going down the same routes as they've always done. To look at other methods. To look at other ways of involvement. And to question what they do at the moment, to question their processes'. George agreed: 'What we're doing is, we're proving that they can do it differently. We've done it our way, following the rules we need to follow, adapting where we need to, you can too, and it won't diminish your research'.

Conclusions

While there are undoubtedly criticisms of emancipatory research (Danieli and Woodhams 2005), and it is more often realised in theory than in practice, it

remains a powerful ideal. 'Patient and public involvement' in research is required by many funders, from UK National Institute of Health Research to the National Lottery-funded DRILL programme. Slowly, people with dementia are being involved in more co-produced research (SDWG [Research Sub-Group] 2014; Stevenson and Taylor 2019; Waite, Poland, and Charlesworth 2019). The Dementia Enquirers project shows that people with dementia can conduct their own research to high ethical standards (Berry et al., 2020). It suggests that people with dementia might sometimes have advantages in working together. It also shows that mainstream research, and research governance, needs to adapt, if people with dementia are to lead their own projects. Not all people with dementia will be capable or interested in this. But many, diagnosed early, are living with dementia for many years, and do not want to be written off.

All the Dementia Pioneers talked about the personal benefits of being heard, through local DEEP groups and the Dementia Enquirers project. Wendy said: 'It's so hard to measure value, but I've seen it for myself in my own group of 'Minds and Voices' of how peoples' confidence has improved, how their opinion of themselves at the beginning of the project might have been zero if they were asked if they felt like a researcher, but how now, they can see the valuable contributions they make are real'. In her blog, she had written: 'I may not remember what we said, I just know that we all share the same values, the same feeling that this project will change people perceptions of what people with dementia CAN achieve'.

This contrasts with the paternalism of some dementia support groups. George said: 'At one project I organise, people with dementia never get a look in…three spouses do the organising, people who haven't got dementia, and they are the people who talk… I can't mute them without saying shut up, because I'd mute the other people with dementia as well. In some meetings it works… and in others it doesn't'. Agnes said she had seen this phenomenon many times, not just in UK but also in European meetings of people with dementia: 'it's very delicate to handle… but sometimes I don't do delicate'. Howard said if it happened on a Zoom call, he would just mute the people who did not have dementia, to stop them dominating.

George talked of how frustrating it was, as an older person, to be written off: 'Because we all come to this with our different life skills, work skills etc, and experience. We as a group of researchers actually have a lot more skills than the researchers have. The researchers only know about research… we know a lot more'. Agnes said 'People forget that we had jobs before, that we had lives before, some of us have held professional roles and attended meetings etc, and yet we're treated as though we are lesser human beings, and that we have an intellectual challenge, and that we're disabled and we've been like that all our lives'. Teresa agreed, 'We seem to get defined by dementia'.

By contrast, Mhari felt that the Dementia Enquirers project would show that someone with dementia was: 'A person being a person, of worth just

for being. Everybody has something to offer, all of us'. Nobody should be written off. Wendy said 'we can get to people with dementia to show them a different way, a different view of themselves, by showing them what we've done. Just to sow seeds…' Or, as Mhari added: 'you can turn everything upside down, in a good way'.

Acknowledgements

Thanks to Rosie Ashworth, David Crepaz-Keay, Dawn Brooker and Lucy Series who were also Advisors for the Dementia Enquirers project. Thanks to Philly Hare and Rachael Litherland for supporting the Dementia Enquirers programme and for comments on this paper. Thanks to National Lottery Community Fund for funding the programme.

Disclosure statement

No potential conflict of interest was reported by the authors.

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