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# Future lived experience: inclusive research with people living with dementia

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## Abstract

People with a diagnosis of dementia have often been the subjects of qualitative research; by contrast, this paper sets out to reflect on the positioning of people living with dementia in inclusive or 'co-produced' research, and the connections between the personal and the collective voice in research. The paper seeks to explore the unique hallmarks of inclusive dementia research, compared with some of the other models of inclusive research. Drawing on our experiences in one study, we describe the stages at which the research was set up, how a group of people living with dementia got involved in doing research, and their role in a conversation analysis of video interaction. We then use short extracts from recorded data of our meetings to discuss some of the tensions and challenges in this type of inclusive research, including political identification, the unequal power balance in inclusive research and the unique contributions of people living with dementia. . Our ensuing argument is for a type of guided spontaneity, where lived experience (and future lived experience) has a space to be valued and to offer insights for research. The implications of inclusive research are about the practical, and about impact. These

messages are contained in a postscript written by the last three authors, who are the members of the dementia research group.

## Key words

Co-production, inclusive research, dementia, power, lived experience, collective voice.

## Introduction

Having dementia is not ordinarily associated with taking on new roles, especially if those roles are clearly of a cognitive nature. With that challenge in mind, this paper discusses some of the implications of people living with dementia having active roles in social research which concerns them. We do this specifically in relation to one project carried out by two university researchers and a group of people living with dementia, but we wish to raise questions and areas of debate relevant to some fundamental issues in democratizing the research process (Edwards and Brannelly, 2017), namely a) the extent to which the personal and the political become connected in inclusive research (Williams, 2011), b) the ways in which power operates between academics and those with lived experience (Walmsley, 2001; Barton, 2005) c) the implications of being researchers with dementia. Over the past two decades, similar issues have been discussed in relation to and by other groups of disabled people, including those with intellectual disabilities (Williams, 1999; Walmsley, 2001; Nind, 2017), people with autism (Pellicano, 2014; Chown et al., 2017) and mental health service users (Staddon, 2015; Kara, 2017). Yet each of these groups can now claim that the doors have been at least somewhat opened to include their voices as researchers, and as 'experts by experience' within that process. Does inclusive dementia research have the same characteristics and issues, or are there some unique hallmarks which set it apart?

Advances in thinking about dementia have been largely due to careful listening and reflection on the views and experiences of those who have a diagnosis (Kitwood, 1997; Lin and Lewis, 2015). However, in traditional research production, as pointed

out by Oliver (1992), disabled people are generally positioned as passive objects. By contrast, emancipatory research which is controlled by disabled people takes a different stance, where the "objects of research" themselves become the researchers, or at least will actively define the research agenda and control the outcomes (Barnes, 2003; Barton, 2005). The original idea of emancipatory research (Oliver, 1992) was based on the social model of disability. It was a turn from medicalised views of impairments, towards social research that would make a practical difference to the lives of disabled people. However, it is hard to find examples of emancipatory research amongst those who need allies, and support to conduct research (Williams, 2011; Williams, Ponting and Ford, 2015; Barton, 2005; Nind and Vinha, 2012). It was for those reasons that the term 'inclusive' was introduced (Walmsley and Johnson, 2003) in the area of intellectual disabilities, since the concept is broad and can encompass a range of approaches. For instance, Clarke et al. (2018) discuss 'participatory data analysis' with people with dementia. We will use 'inclusive' as a term to capture all of these ways of involvement, but will also mention 'co-production' (Boyle and Harris, 2009), which was how our study was generally framed. Although 'co-production' implies more of a sense of agency for co-researchers, we agree with Kara (2017) that 'co-production does not necessarily lead to empowerment' (p. 297). 'Inclusive research' is not without its critics and its challenges, both from Disability Studies scholars (Barnes, 2003; Carr, 2019) and from methodologists claiming that inclusive research will be biased towards 'users' views', who may be activists, and not representative of others. It has also been suggested that such partnerships with activists may fail to produce change (Gelech et al., 2018, p 177).

Although our main focus here is on the inclusive *process*, we shall outline below the methodology of the project which the Forget-me-Not members joined. In the second part of the paper, we outline the roles taken up by members of the dementia research group, and then reflect on the light this project sheds on current debates in co-produced research in the three 'Reflections' sections. Finally, we return to a brief discussion to summarise what this project has revealed about the potential for an inclusive approach which is methodologically robust and we include a postscript dictated by the three members of the Forget-me-Not group after reading and agreeing a summary of this article.

## Background: attitudes towards dementia

Society's view of dementia, at least in the UK, is overwhelmingly as a tragic illness (Boyle, 2010), with an emphasis on the lack of personhood which dementia might entail as the disease progresses (Sabat and Harre, 1992). The practice emphasis in social care for people with dementia has tended to be on nursing and residential home care, rather than community based supports (Wanless et al., 2006, p.514), and on dignity rather than autonomy (Boyle, 2010, p.512). Conversely, much of the literature (Harris and Keady, 2008; Lin and Lewis, 2015) and policy (Department of Health, 2015) about dementia focuses on creating 'more dementia friendly communities', so that people can 'live well' with their condition and there is a policy emphasis on the autonomy and decision-making capacity of people with dementia (Department of Health, 2015). Clearly there is a multiplicity of perspectives on dementia, reflected both in practice and policy (Innes and Manthorpe, 2012). Where, however, are the views and the agency of people with dementia themselves? As Innes and Manthorpe (2012, p.686) acknowledge, their views are generally missing, and historically they have been assumed to be unable to contribute to understanding the condition (Cottrell and Schultz, 1993). However the opportunities for people with dementia to engage as active participants in international policy (Shakespeare, Zeilig and Mittler, 2017) and as participants in qualitative research have expanded (Carmody et al., 2015; Dewing, 2002; Hubbard, Downs and Tester, 2003; McKeown et al., 2010 ), allowing research to shed a better informed light on what it means to 'live with dementia'.

## Doing Conversation Analysis: the 'Getting Things Changed' project

This article draws on a study entitled 'Getting Things Changed' in which the three final authors formed a research group. We call it here the 'Forget-me-Not'group, as that was the day activity centre from which members were recruited, a centre set up for people with 'early onset' dementia. Although this paper does not seek to report on the research itself, the following section describes some of the methodology used and the eventual findings, as background for reflections about inclusive research processes.

The research came about as part of a larger co-produced project about changing practices which exclude or 'misfit' (Garland-Thomson, 2011) disabled people. This

wider study, funded by a UK government research council, has the full title of 'Tackling Disabling Practices: co-production and change' and is known as 'Getting Things Changed'. The focus on dementia came about in the context of one strand of the research, where the initial goal was to find out whether conversation analysis (CA) of video recordings of natural interactions could be useful in creating change in the practices of support staff and carers. This built on existing interests in the research team (Antaki & Webb, 2019; Williams, 2011; Antaki et al., 2007; Antaki, 2011) who have applied CA to analyse naturally occurring interactions between disabled people and their support workers.

By the end of the data collection phase, we had almost ten hours of video data involving 28 participants, filmed largely in activity or memory groups where people living with dementia were interacting with staff members, volunteers or others. These ranged from a video taken on a car journey where two people with dementia had a lift home from a volunteer driver, several videos of games and quiz-type activities in groups, and conversations which focused on reminiscences or shared interests. This strand of the research was approved by the national Social Care Research Ethics Committee, who approved the plan to seek personal consultees for those who lacked capacity to consent for themselves (Mental Capacity Act 2005). The project used accessible information sheets and a short recruitment video made by the 'Forget-me-Not' group and Webb obtained consent from participants over a series of repeated visits, explanations and familiarisation. Not everyone consented to be filmed, but we were confident that those who did had an understanding of the purpose of this research, which was about improving the conversations or activities in which they participated.

The focus was on the interactional outcomes of specific strategies or patterns in the talk, not the communication difficulties of the people living with dementia (Webb, 2017). Our findings are reported elsewhere (Antaki and Webb, 2019; Williams, Webb et al., 2019) but it is worth mentioning that we became particularly interested in questions posed by supporters, and how they were taken by the person living with dementia. As is generally the case in CA, decisions have to be made about which phenomena (and indeed which extracts) are analytically interesting, as we discuss below. For instance, we noticed that closed 'known answer' questions tended to

focus on memory loss, and often led to difficulties in the response. That was happening both in one-one talk about the past, and also in group activities like quizzes. We have written in the CA literature both about the epistemic asymmetries visible in talk about the past (Williams, Webb et al., 2019) and about how people's choices in day activity groups may be overridden by staff whose main goal is to complete an activity (Antaki and Webb, 2019).

## Including researchers with direct lived experience

The rationale for the wider study was about the control and voice of people identifying as disabled, and had been set up in co-production with Disability Rights UK. The ethos in the research was inclusive, driven by the premise (Oliver, 1992; Barnes, 2003) that the direction and outcome of disability research must be determined by disabled people themselves, and their representative organisations. Previous studies in which members of our team had been involved (Williams, Ponting and Ford, 2009) showed how people with intellectual disabilities (ID) can take a meaningful role, even within seemingly technical research methodologies such as CA (Williams, 2011).  Thus the opportunity to work in this way with people living with dementia fitted our overall goals to co-produce the research, and as it emerged, became central to this part of our project.

Via the project advisory group, Williams and Webb initially approached the Dementia Empowerment Network (DEEP) and got in touch with the Forget-me-Not group. Their first meeting at the centre was to seek advice about the goals and methodology in the research. The three final authors quickly chose to take an interest. At the time we started the project, we were all between the ages of 55 and 70, having had diverse diagnoses, but all classified as 'early onset dementia', some ten years previously. Two of us are men, and one is a woman, and importantly we already knew each other as close friends.

First, the group showed that communication matters to them. At Meeting 1 for instance, Williams noted afterwards that: 'one of the main messages they had about communication was about giving time – allowing people time to think, to find words, to respond'. Corresponding to this, Webb noted from that same meeting that:

"It was clear how frustrating it was for people to lose bits of info. Interestingly, people didn't immediately jump in to help them or provide answers, but often the person searched for the word in silence and then carried on". (Meeting 1, notes)

Since then, while creating the recruitment video for the project, Sandy Read said spontaneously on camera:

"It does help to talk to people. That's what this research is about. Do you have somebody to listen to you? If you don't, find someone who will listen to you, just talk to them… But this research, down the line, could give a whole new aspect to someone's life." [4, video)

If there were doubts about persuading the group to take part in the research, at least this type of engagement reassured us all that communication matters.

In terms of the research protocol, however, Williams and Webb immediately learnt from the group members that assumptions about support staff were not going to work. The group members all have a degree of independence, can communicate verbally and manage their own lives. But even amongst those in more advanced stages in the Forget-me-Not centre, no-one had one-one support or care workers. Instead they benefited from various group activities, where paid or volunteer staff interacted with them. Therefore the focus was changed from 'support worker' to 'conversation partner', a generic term for anyone who interacted with a person with dementia.

Subsequently, the Forget-me-Not research group had on average one meeting a month, where Williams would visit, at first in the premises of the Forget-me-Not centre itself, but subsequently in the home of one of the research group. Thus the original plan to engage people as advisors expanded and deepened, and we were fortunate to have enough flexibility in funding for this to happen. During this time, Webb had started to collect video data from the sites which had consented to take part in the research, and our main activity in the research group was to watch through the videos, discussing and re-enacting scenes we had watched. The contribution made by Forget-me-Not members was to help identify what was interesting in the data; as mentioned, CA does rely on some measure of selection of key extracts, and the principle we followed was that the Forget-me-Not group's insights, based on their own personal experience, would help us focus on what

mattered. We followed a strict ethical protocol, with all the data being collected in areas where the Forget-me-Not group had no contact or familiarity, so that confidentiality was maintained.

The nature of the group members' involvement, and contributions to the research outcomes, are explored below. In the event, this was more than simply identifying extracts of interest, and involved exploring in detail how interaction works. We return below to recordings of our meetings, which are summarised in Table 1, so that the reflections are grounded in what actually happened, although this paper itself does not aim to present a detailed CA analysis. In the following sections, we shall consider how the social activity of research is made visible, and is constructed within, the interactions between group members and academic researchers.

## Reflections on inclusive research

### The personal and the collective voice

The concept of having a voice, as a person with dementia, has become increasingly prominent over the past twenty years (Beard, 2004; Bartlett, 2014; Shakespeare et al., 2017; Bryden, 2015). One of the key aims in collaborating with the Forget-me-Not group was to understand better what it takes for the voices of people with dementia to make a difference. Therefore, the formation of this research group was an exciting and extremely relevant moment for the project. However, the notion of 'voice' is never entirely straightforward.

Identifying with others may be the first step from individual voice towards collective voice (Barnes and Cotterell, 2012, pp 76-9). For one individual to 'speak up' for people with dementia, a minimal requirement is that they identify with others living with dementia.

### Extract 1 (Meeting 12: video)

1. C[1]: I was saying that somebody's strengths is somebody else's weaknesses. So
2.     you just turn it around, and everybody helps themselves. And what I can do,
3.     you can't do. So we do it together.
4. E: Yeah

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[1] In all extracts C, D and E are group members, A and B are university researchers.

5. C: Don't we?
6. E: Yeah I think you're right with this.

In this video extract, group members were reflecting on the ways in which they could support each other, with one person for instance being the one who could help with physical difficulties, and another making sure that people did not get lost. 'Doing it together' as they articulated at line 3, is the key for them.

A collective stance may start from this basis of peer support and friendship, but it is more than that. Moving from an individual to a 'collective' voice is a central plank of inclusive research with other groups, such as people with intellectual disabilities (Williams, 2011). That process implies there is some recognition of the commonalities in the oppression faced by the wider group, as in emancipatory research based on the social model of disability (Oliver, 2013). In some projects, as argued by Stone and Priestley (1996) achieving that collective, political awareness can be a journey of discovery during the research itself. In the current project, the Forget-me-Not members did not routinely identify with the word 'disabled', associating that word with functional deficits later on, and had no connection with the disability movement. However, we often discussed the ways in which societal attitudes affect people with dementia, and thus effectively bought in to a 'social relational' model of disability, in the sense in which Thomas (2004) suggests that people might be disabled both by their bodily (or cognitive) impairments, but also by the way in which they are treated by others in society.

Dementia experience can be very varied, extremely individual, and will change as time moves on. Therefore, the video data we all watched together opened up a picture of what other people with dementia might experience, particularly via activity groups and memory cafes (of which the Forget-me-Not members had little experience). Nevertheless the research group members brought to these scenes a critical 'insider' eye, noting for instance after watching a data extract of a quiz in a dementia activity group, that these groups were often run in unsuitable premises with poor acoustics.

**Extract 2 (Meeting 9, video)**

1. A: So what did you reckon?
2. E: (pause) Mayhem.
3. D: Yeah
4. E: Absolute chaos.
5. A: (laughs) it was wasn't it?
6. D: Yeah
7. A: Do you think that matters? Would it be better to have it smaller?
8. D: Structured.
9. E: It could have been done in a quieter room.
10. A: Yeah
11. E: These rooms nowadays are – laminate flooring, there's nothing there to absorb the noise.

It is notable here how the laughable attributes of 'mayhem' and 'absolute chaos' lead directly to A's intervention at line 7, with a positively tilted question about having a smaller group activity. This receives a preferred response at line 8, 'structured' being another attribute of a more orderly quiz. E then immediately follows that with the point about acoustics, which had indeed added to the confusion of questions and answers in the quiz data we were watching.  It is one step from this type of observation to move, as E does, to 'these rooms nowadays', pointing out that dementia groups are often run in unsuitable premises.

Routinely, group talk started with personal experience or a story from the past, and moved towards a more generic stance about rights. In Meeting 11, for instance, one group member spoke about the importance of rights, springing directly from the very personal and frightening experience of being diagnosed with dementia:

**Extract 3 (Meeting 11, audio)**

C:     I don't know where it came from, for all this panic to set in, and think that because I've got it, all of a sudden I feel I don't have rights. And people who are in, you know, caring for me, have taken all those rights away from me, and they're doing it for me, and I don't have the say in it.

Inclusive research in which people use their lived experience will always have that campaigning edge to it (Gelech et al., 2017), and is strongest when the project is designed so that members have the freedom to develop their own consciousness and action via what we have termed 'back stage' events in the research – that is, discussions and free conversation during meetings or informal chats over coffee.

Preparing for a 'front stage' event (in this case, a recruitment film, and two workshop presentations) would be, according to Goffman's (1967) notion, a chance to construct the role that one might later perform. However, it was noticeable here that 'being a person with dementia' is enacted throughout each encounter in rather unpredictable ways. The group members prepared, for instance, a powerpoint presentation for the first project workshop. It contained in itself both the personal and the wider implications. For instance, a phrase from the planning meeting was: 'The slow, slow drip when people saw me as a lesser person', and that found its way onto the slides, moving directly into how people can stand up for their rights. In the event, the talk became about personal identity and stories of diagnosis. It was very powerful, precisely because of the way in which memory problems were visible in *what* was said and *how* it was said.

 Thus inclusive qualitative research with people living with dementia is, first of all, a 'leaky' process, where the unique experience of dementia means that there is a certain authenticity in the moment-by-moment presentation of the self. The personal can slide into group activism, and vice versa – literally going from 'I' to 'we'. In the next section we move behind the scenes to see how these ideas came about.

**Power and partnership**

Inclusive research can easily become tokenistic (Chappell, 2000; Nind and Vinha, 2012). The original concept of 'emancipatory' research was that disabled people would lead and control the whole process, but where academics have a role, there is often suspicion that projects such as the current one are initiated and steered by them.  These matters are visible in the detail of the conversation which goes on back stage. Here is an extract from an early meeting, in which the three group members

had agreed to advise on the research protocol, and where we were discussing how to refer to 'dementia' on the participant information sheets:

**Extract 4 (Meeting 2, audio)**

1. A:  Well this is the thing, isn't it, it's a sensitive thing when you're approaching

2.     people, how they refer to themselves really.

*3.* C:  I mean we've had a lot of people coming in [to this centre] and looking

*4.*     around,  but you never see them again, you know. They've got this thing in

*5.*     the back of their mind, you know, that there's nothing wrong with them. *I*

*6. don't need this place, I'm fine.*

7. A:  Which is why we thought perhaps if we just said *memory problems,* as well,

8.     that kind of covers a wider thing. But I don't know whether that fudges it, or

9.     makes it...

10. D:  No, it doesn't fudge it. Because I came here just with memory problems, and

11.     it led to dementia. So people- it's a way of introducing people that don't

12.     accept, they haven't got dementia. Do you know what I mean?

13. A:  Yeah.

14. D: So it's a gradual process.

15. A:  So you think that's OK.

16. D:  I do.

At line 1, A introduces the sensitivity of approaching people who might have a diagnosis of dementia, to take part in a research project in which they would have to acknowledge that label. C's remark in lines 3-6 is thus very much 'preferred' or in tune with what was suggested, that not everyone will think of themselves as having dementia. A's suggestion at line 7 thus leads off the topic which C had taken up. However, it is framed in a 'why we thought perhaps': albeit hesitantly, A introduces 'memory problems' as something which the research team had already considered, giving it some authority as a term. Although she immediately downplays her decision to use that term ('I don't know whether that fudges it'), C backs it up completely, re-interpreting A's worries about the vagueness of the term, as something which is bound to happen during a gradual journey towards acknowledging dementia. One can see how easy it is for leading questions to influence the course of the interaction, and here they lead to additional justification from group members for A's original suggestion.

It is worth noting also the role of payment as a token of power. Paying the research group directly (Devotta et al., 2017) proved difficult in the present project, since the Forget-me-Not centre is in fact a centre run by a Health Trust. The preferred solution was to accept 'token' payments, at a level which attempted to recognise the hours and expertise put in to the project. Despite its empowering nature and practices, the Forget-me-Not centre was subject to the assumptions embedded in health provision, that the 'service users' were recipients of some therapy or support, and not contributors who could be paid.

In order to start achieving some kind of equality, it is necessary to step back and 'give away' one's power. As Williams, Simons et al. (2005) pointed out, power sharing becomes visible if and when the disabled partners start to challenge and create their own agenda, and this is a gradual process. For instance, in the current project, the academic team was surprised by the extent to which dementia groups in the video data engaged in games and quiz-type activities, and felt that some of this may disadvantage the clients with dementia. At the least, one could say that they can become childish and over-organised; at the worst, some participants were put on the spot, unable to respond, and excluded from meaningful participation. However, the Forget-me-Not members memorably said that assumption was wrong. In Extract 5 we had all re-watched a video segment, where it felt to A that conversation had been shut down by the demands of the quiz. However, that was not exactly what C thought.

**Extract 5 (Meeting 9)**

1. A: The aim of all of this – in a way you're trying to get conversation started. But did
2.    you, did you think they actually did?
3. C: Oh it was brilliant. They all told each – they knew where they came from didn't they
4. A: Yeah? yeah
5. C: And they brought up memories didn't it.
6. A: It DID bring up memories  (9 lines about the specifics of the video)
7. A: Yeah yeah
8. C: But it did bring up conversation didn't it?
**9.** A: Yes, cause he started didn't he

A's assumption that the quiz was harmful to open conversation in the group was contained in the negatively tilted question in lines 1-2, but C responded to this in an unexpected way at line 3, and continued to argue that the video extract we had watched was 'brilliant' because the quiz 'brought up memories' (line 6) and 'it did bring up conversation' (line 8). Thus the authority of the academic's viewpoint was not upheld here, and A's responses contain just minimal agreement tokens 'yeah yeah'. In many other instances, we have recordings of discussions in the Forget-me-Not group where members confidently asserted expert opinions, with views which gained validity because they were explicitly built on experience. Typically, there was a trope of 'I know what that's like', the right to know about one's own life.

This is not to say that power dynamics are unimportant or negligible. The structuring of this particular project was such that Forget-me-Not members were asked to perform specific tasks – namely giving generic advice about dementia, responding to video data of other dementia groups, and (as we went along in the project) re-enacting scenes to develop ideas of how these conversations could be more successful. The idea of doing this type of fine-grained analysis of interaction came from the academics, and so Forget-me-Not members were simply joining in and supporting other people's research ideas, echoing Bigby's (2014) idea of a partnership project. As we shall see in the Postscript to this article, however, that does not mean they had no ideas of their own for research, and they have firm ideas about what matters in research.

Sharing the organisation of the research at a practical level has been both fun and equalising, with the sharing of jokes, the enjoyment and the fun of supporting each other in a group. Suffice to say that group members have more than sufficiently contributed to that process.

**Being researchers living with dementia**

Although this paper does not set out to discuss our research findings, the process of inclusive research can only be understood with some examples of what the group has achieved. As mentioned, the methodology in this part of our research is conversation analysis (CA), which involves detailed analysis of videos of 'naturally occurring' interactions in dementia groups, as in Chatwin (2014). Often considered a rather technical and difficult method to learn, it

may appear surprising to find it associated with inclusive research where people with dementia are active co-researchers; that was also true with previous inclusive CA research with people with intellectual disabilities (Williams, 2011). It is worth considering therefore how meaningful the involvement of Forget-me-Not members actually was in producing the final analysis.

An example of how we worked occurred during Meeting 8, which was the first time we had watched video data collected by Webb. The video clip we watched contained two women in a car on their journey home from a day centre, chatting with their volunteer driver 'Bob'. Webb had already spotted some potentially interesting things going on in the conversation, when Williams took the film to the group members. At one point the driver started up a conversation with 'Did you have a nice meal today?'. Both women in the car found it easy to answer 'Yes' to that. However, as we often do when asking a question, he did not leave it at that, and he tried to get more detail with 'Can you tell me what it was?' That more specific question, which did not contain any prompts, caused problems for the two passengers. The first lady came up with 'fish fingers', although she was hesitant, but the other woman was not sure what she had eaten. One of the Forget-me-Not group immediately spotted this, and we discussed how questions can be difficult, a type of conversational problem which they subsequently returned to.

**Extract 6** Meeting 8

"With my friend it happens, yeah. She gets home, her sister will phone, say, 'Where did you go today? What did you have to eat?', and she can't answer it. She doesn't know. She'll make up anything."

From Meeting 8 onwards, the group agreed to try out these conversations by acting them out themselves; more than anything else, that method probably helped to appreciate the detail of what was going on in the conversation, and to suggest alternatives. We looked for instance at how one might prompt someone to remember something, and suggested that could be 'demeaning'. It is possible to have a car journey where no-one is asked for facts, as was illustrated by the subsequent role-play the [Group] did. The point here was that the driver did not need to ask questions, but to simply accept and appreciate what the passengers noticed.

Following this, we then watched some other clips, mainly filmed inside activity groups of various kinds, and they included some conversations in which support staff had found it very difficult to get any meaningful responses to the question 'Do you remember?' Here is a short excerpt from our discussion.

**Extract 7** (Meeting 11)

1. A: So if you know the answer to a question already, and you want to get somebody
2.    talking about it, what do you do?
3. E: Cup of tea to start with. 'Cup of tea?'
4. C: Yeah. 'Cup of tea?'
5. D: Yeah. Relax. One person. One-to-one, rather than one-to-two, you know. He feels
6.    outnumbered.
7. E: Like, 'I understand you used to be an engineer, doing air conditioning. Can you tell
8.    me more?'
9. A: That's fantastic, E. That is it, isn't it.
10. E: Yeah. 'What did that entail?'
11. C: Yeah.

Group members had already spotted here that staff asked questions to which they already knew the answer. That happened routinely in memory talk. Thus the way in which Forget-me-Not members contributed insights was by suggesting alternatives. The first suggestion (lines 3-5) concerns how one could make the occasion more relaxed. We also felt that a one-one conversation is important, rather than having two people asking questions of one man (E had previously termed this an 'interrogation'). E then role-played how he would avoid asking a difficult question, by leading in with an opener that revealed what he already knew about the man's past job. We could all see that the 'Can you tell me more?' (line 8) would be a more productive question, positioned after the sharing of some detail to start the memory talk.

Although Forget-me-Not members did not use CA terms, all this is the stuff of CA: the sequential position of an utterance matters in the talk and is consequential for what comes next (Schegloff, 2007); the analyst attends to the way in which one participant interprets or responds to the previous turn (Sacks et al., 1974); and there is a recent stream of CA centred on 'epistemics' (Heritage, 2013) , the interplay in conversation of who knows what, and indeed who has the right to knowledge. As the

project proceeded, the analytical insights of the group members were a constant source of inspiration. There were flashes of really detailed appreciation of how social interaction works, both in the data watched, and via re-enactments and role-plays.  Group members were also extremely sensitive to body language: at one point in the data, an older woman with dementia was having difficulty answering questions in a quiz, and she got totally cut out of the conversation when two other people took the paper from her and literally turned their backs on her. When we re-enacted this part during Meeting 12, C took the part of the woman, and became quite upset when experiencing rejection. Even though she knew it was simply role-play, she explained afterwards:

"I get upset because this happens to me. It's not nice when someone cuts you out, or thinks you've got nothing to say for yourself."     [Meeting 12]

Group members contributed to analysis via personal experience.  People with acquired disabilities are acutely aware that the power to remember and to competently advocate for rights could soon be undermined. In one discussion the Forget-me-Not group went on to express profound concern to record advance decisions, in case people 'took away the right' to make decisions autonomously. The words show an awareness of the here-and-now, and continually make reference to present experience. Discussions often then moved towards a future perspective, where advancing illness could mean loss of activity and independence.  Thus our final conclusion here is that being a researcher with dementia is not just about bringing 'lived experience' to the table. It is also about bringing 'future lived experience', and there is bound to be a very sensitive and difficult balancing act to perform, which draws not only on past and present identity, but also an imagined future.

**Discussion and postscript**

We started this paper with a question: is 'inclusive research' by and with people living with dementia a distinct activity from other types of inclusive research? The answer of course is not definitive, since this paper simply draws on one research project, with one group of people. However, our research could claim to be amongst the most methodologically difficult and rigorous in the qualitative sphere, as CA analysis is always grounded in evidence and built on the most detailed technical

body of knowledge about interaction. Thus in some ways we were pushing the boundaries in what we attempted together.

A collective voice for people living with dementia cannot be taken for granted: that is also true with other marginalised groups. In our case the discussion about what 'disability' means in terms of social barriers and attitudes became part of the research process, with particular attention to the social relational: the social attitudes and lack of respect shown by other people.

Since this article was first submitted, fifteen months have elapsed, and during that time much has changed. The Forget-me-Not members have continued to work on a smaller impact grant with Webb, and produced a series of training films based on the research (Forget-me-Not group, 2019: http://www.bristol.ac.uk/sps/gettingthingschanged/).  This step was essential, and the Forget-me-Not members in many ways flourished with this dynamic and tangible product from the research. People living with dementia can identify and reach out to others precisely by leading on the *products* of the research, rather than simply being involved in the *process* (Webb et al., 2019). Further, since the end of the project, Forget-me-Not members expressed strong views about what *they* wanted to research, and initiated a small exploratory project, supported by Webb and other colleagues, to explore the experience of post-diagnosis support from the point of view of other people living with dementia. Thus the leadership and agency of the Forget-me-Not members have come to the fore in these more tangible activities, which had been started off from concerns about impact. These matters seem absolutely essential to moving forward towards an emancipatory stance in inclusive dementia research, and Forget-me-Not members have themselves have written a postscript below.

A final point has to be raised about what the Forget-me-Not group actually contributed towards robust findings and impact. In terms of the latter, repeated evaluations by practitioners and professionals have stressed that it was the involvement of the Forget-me-Not members' 'direct voice' that made the difference in the training package, particularly because their 'front stage' performance was so authentic. The academic team has also reflected elsewhere (Williams, Webb et al., 2019; Webb et al., 2019) that their contribution enabled

them to have some faith that the interactional details reported really mattered to people living with dementia. That in itself is a contribution to the field of CA, and challenges the practice oriented branches of the methodology (Antaki, 2011) to consider both practitioners and people living with dementia as equal social actors.

Time and 'future lived experience' are key to inclusive dementia research. Relationships in the team, confidence and skills all took time in this project, as has been noted in other types of inclusive research (Abbell et al., 2007); unfortunately, time is sometimes in short supply for people living with a progressive disease. There is a real practical tension here between the need to do things thoroughly in a research project, and the need to act fast with people who are literally living for the day. However, insights about time lie at the heart of what people with dementia have to offer, as will be seen in the words of Forget-me-Not members with which we conclude.

**Postscript: Roy James, Sandy Read, Harry Davis.**

We are the ones living it – experiencing dementia. We don't need some academic or doctor telling us how we should be living it. We all have the experience of being diagnosed with dementia, which can be so cold and calculated. Before we got our diagnoses, we were doing what we wanted and we had free choice of what we wanted to do. Once we got a diagnosis, things started to change, and we felt that we were being treated like children. That's when we started to rebel.

Thinking about the future, it's heart-breaking to see people who have lost their capacity to make decisions. Images showing people with dementia are often not very positive. And the first contact the public have with people living with dementia is what they see on the TV. And that's scary. We want to be respected, and to have our opinions listened to, and we still want to have that in the future. When we see people being ignored and not brought into the conversation, for instance that really affects us. Doctors should not speak to the family member we happen to be with, they should talk to us directly.

We got involved in research because we thought it was important to make a difference to other people. The important thing is to listen and discuss, and not be told what is happening.  If you start telling people what they should do, then you

lose the point. People think 'Why am I being told what to do?' So when you're doing research, choices shouldn't be taken away. When you ask people what they want to do, then you should go with it – within reason, as long as it's legal.

Through research we've been able to make our feelings felt, and we've met other people. We feel empowered. The research went with the flow, and that's a good way to be. We live in the moment, because we have to. We forget yesterday, so today is important. Today is the moment. We can teach that to other people. If everyone had dementia, what a wonderful world it would be. The trick is not to worry about tomorrow.

Our message to other people with dementia who may want to do their own research: we'd want to say to everyone that research can give you confidence, to be able to talk. Watch our videos and then come back to ask us. Don't be afraid to ask questions and to disagree, and challenge other people. It's our time to be opinionated, it's fine if people don't always agree. But we want our films to be seen and to be used. So it's important to get feedback from others who have watched the films. Although we've done this research, we don't want to feel we've wasted our time. We don't want to hear that others haven't got the time to take action.  So we want feedback from the research.

One person with dementia isn't strong on their own. You need a group, to force people to sit up and take notice. Together we can still be full of life – 'Never give up your dreams'.

*The dementia communication training videos can be accessed at:* [http://www.bristol.ac.uk/sps/gettingthingschanged/](http://www.bristol.ac.uk/sps/gettingthingschanged/)

**References**

Abell, S., Ashmore, J., Beart, S., Brownley, P., Butcher, A., Clarke, Z., Combes, H., Francis, E., Hayes, S., Hemmingham, I. and Hicks, K., (2007). Including everyone in research: The Burton Street Research Group. *British Journal of Learning Disabilities*, *35*(2), pp.121-124.

Antaki, C. (ed) (2011) *Applied Conversation Analysis: Intervention and Change in Institutional Talk*. London: Palgrave.

Antaki, C, Walton, C. & Finlay, W. (2007). How proposing an activity to a person with person with an intellectual disability can imply a limited identity. *Discourse and Society*, 18, 393-410.

Antaki, C., & Webb, J. (2019). When the larger objective matters more: support workers' epistemic and deontic authority over adult service-users. Sociology of Health & Illness. doi: 10.1111/1467-9566.12964

Barnes, C. (2003). 'What a Difference a Decade Makes: reflections on doing 'emancipatory' disability research'. *Disability & Society, 18 (1),* 3-17.

Barton, L. (2005) Emancipatory research and disabled people: some observations and questions. *Educational Review, 57 (3): 317-327*

Barnes, M. & Cotterell, P. (eds) (2012) *Critical Perspectives on User Involvement.* Bristol: the Policy Press.

Bartlett, R. (2014). Citizenship in Action: the lived experience of citizens with dementia who campaign for social change. *Disability & Society*, *29 (8)*, 1291-1304.

Beard, R.L. (2004). Advocating voice: organisational, historical and social milieux of the Alzheimer's disease movement. *Sociology of Health & Illness*, *26(6)*, 797-819.

Bigby, C., Frawley, P. & Ramcharan, P. (2014) Conceptualizing Inclusive Research with People with Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities, 27: 3-12.*

Boyle, D. and Harris, M. (2009) *The Challenge of Co-production: how equal partnerships between professionals and the public are crucial to improving public services.* London NEF/NESTA.

Boyle, G. (2010). Social policy for people with dementia in England: promoting human rights. *Health and Social Care in the Community*, *18(5),* 511-19.

Bryden, C. (2015). *Nothing About Us Without Us*. London: Jessica Kingsley.

Carmody, J., Traynor, V. and Marchetti, E. (2015) Barriers to Qualitative Dementia Research: The Elephant in the Room. *Qualitative Health Research,* 25 (7): 1013-19.

Carr, S. (2019): 'I am not your nutter': a personal reflection on commodification and comradeship in service user and survivor research, Disability & Society, DOI: 10.1080/09687599.2019.1608424

Chappell, A. (2000) Emergence of participatory methodology in learning difficulty research: understanding the context. *British Journal of Learning Disabilities, 28: 38-43.*

Chatwin, J. (2014). Conversation analysis as a method for investigating interaction in care home environments. *Dementia, 13 (6)*, 737-746

Chown, N., Robinson, J., Beardon, L., Downing, J., Hughes, L., Leatherland, J., Fox, K.,
Hickman, L. and MacGregor, D. (2017) 'Improving research about us, with us: A draft framework for inclusive autism research', *Disability & Society*, 32:5, 720-734.

Clarke, C. L., Wilkinson, H., Watson, J., Wilcockson, J., Kinnaird, L., & Williamson, T. (2018). A Seat Around the Table: Participatory Data Analysis With People Living With Dementia. *Qualitative health research*, 1049732318774768

Cottrell, V. and Shulz, R. (1993). The perspective of the patient with Alzheimer's disease: a neglected dimension of dementia research. *Gerontologist, 33(2),* 205-11.

Department of Health (2015) *The Prime Minister's Challenge on Dementia 2020*

Devotta, K., Woodhall-Melnik, J., Pedersen, C. et al.. (2017) Enriching qualitative research by engaging peer interviewers: a case study. *Qualitative Research,* 16(6) 661–680.

Dewing, J. (2002). From ritual to relationship: a person-centred approach to consent in qualitative research with older people who have a dementia. *Dementia*, *1(2),* 157-171.

Edwards, R. and Brannelly, T. (2017) Approaches to democratising  qualitative research methods. *Qualitative Research,* 17(3) 271–277.

Garland-Thomson, R.  2011.  "Misfits: A Feminist Materialist Disability Concept." *Hypatia* 26 (3): 591–609.

Gelech, J., Desjardins, M., Matthews, E. & Graumans, R. (2017) Why do working relationships not change? The need for a new approach to disability partnership research and social change. *Disability & Society*, 32:2, 176-192.

Goffman, E. (1967) *The Presentation of Self in Everyday Life.*

Harris, P. B., & Keady, J. (2008). Wisdom, resilience and successful aging: Changing public discourses on living with dementia. *Dementia*, *7*, 5–8.

Heritage, J. (2013), 'Epistemics in conversation', in Sidnell, J. and T. Stivers (eds), The Handbook of Conversation Analysis, London: Blackwell, 370–94

Hubbard, G., Downs, M. G., & Tester, S. (2003). Including older people with dementia in research: challenges and strategies. *Aging & mental health, 7(5)*, 351-362.

Innes, A. & Manthorpe, J. (2012). Developing theoretical understandings of dementia and their application to dementia care policy in the UK. *Dementia, 12(6)*, 682-696.

Kara, H. (2017) Identity and power in co-produced activist research. *Qualitative Research,* 17 (3): 289-301.

Kitwood, T. (1997). Dementia reconsidered: The person comes first. Buckingham: Open University Press.

Lin, S. & Lewis, F.M (2015). Dementia friendly, dementia capable, and dementia positive: Concepts to prepare for the future. *The Gerontologist*, *55 (2),* 237-244.

McKeown, J., Clarke, A., Ingleton, C., & Repper, J. (2010). Actively involving people with dementia in qualitative research. *Journal of clinical nursing, 19(13-14)*, 1935-1943.

Mental Capacity Act c.9 (2005) https://www.legislation.gov.uk/ukpga/2005/9/contents

Nind, M. (2017) The practical wisdom of inclusive research. *Qualitative Research* 17(3) 278–288.

Nind, M. & Vinha, H. (2012). Doing Research Inclusively: bridges to multiple possibilities in Inclusive Research. *British Journal of Learning Disabilities, 42 (20),* 102-109.

Oliver, M. (1992). Changing the Social Relations of Research Production? *Disability & Society, 7 (2),* 101-114.

Oliver, M. (2013). The social model of disability: thirty years on. *Disability & Society, 28 (7)*, 1024-1026.

Pellicano, L. (2014) 'A future made together: New directions in the ethics of autism research', *Journal of Research in Special Educational Needs*, 14(3), pp. 200-204.

Sabat, S., & Harre´, R. (1992). The construction and deconstruction of self in Alzheimer's disease. *Ageing & Society, 12,* 443–461.

Sacks, H., Schegloff, E. A., & Jefferson, G. (1974). A simplest systematics for the H organisation of turn-taking for conversation. *Language*, 50, pp.696-735.

Schegloff, E. A. (2007). *Sequence organization in interaction: A primer in conversation analysis I* (Vol. 1). Cambridge University Press.

Shakespeare, T., Zeilig, H. and Mittler, P. (2017). Rights in Mind: thinking differently about dementia and disability. *Dementia,* 18 (3), pp 1075–1088.

Staddon, P. (2015) *Mental Health Service Users in Research: Critical Sociological Perspectives* Bristol: The Policy Press

Stone, E., and M. Priestley. 1996. "Parasites, Pawns and Partners: Disability Research and the Role of Non-Disabled Researchers." *British Journal of Sociology* 47 (4): 699–716.

Thomas, C. (2004) How is disability understood? An examination of sociological approaches. *Disability and Society*, *19 (6),*569-583.

Tøssebro, J. (2004). Understanding disability: Introduction to the special issues of SJDR. *Scandinavian Journal of Disability Research, 6(1)*, 3-7.

Walmsley, J. (2001). Normalisation, emancipatory research and inclusive research in Learning Disability. *Disability & Society, 16 (2),* 187-205.

Walmsley, J. and Johnson, K. (2003) *Inclusive Research with People with Learning Disabilities: Past, Present and Futures.* London: Jessica Kingsley.

Wanless D., Forder J., Fernandez J. et al. (2006) *Securing Good Care for Older People: Taking a Long-term View.* King's Fund, London

Webb, J. (2017) Conversation takes two: understanding interactions with people with dementia, *Disability & Society,* 32:7, 1102-1106

Webb, J., Williams, V., James, R., Read, S., & Davis, H. (2019) Communication training: creating videos together, Journal of Dementia Care, 27 (3): 36 – 38.

Williams, V. (1999) Researching Together. *British Journal of Learning Disabilities,* 27 (2): 48-51.

Williams, V. (2011) *Disability and Discourse: analysing inclusive conversation with people with intellectual disabilities.* Chichester: Wiley-Blackwell

Williams, V., Ponting, L. & Ford, K. (2015) A Platform for Change? Inclusive research about 'choice and control'. *British Journal of Learning Disabilities,* 43 (3): 106-113.

Williams, V. , Ponting, L., Ford, K. and Rudge, P. (2009) 'I do like the subtle touch': interactions between people with learning disabilities and their personal assistants. *Disability and Society.24 (7): 815-828.*

Williams, V. , Simons, K. and Swindon People First Research Team (2005) More Researching Together. *British Journal of Learning Disabilities,* 32: 1-9.

Williams, V., Tarleton B., Heslop, P, Porter, S., Sass, B., Blue, S., Merchant, W. and Mason-Angelow, V. (2018) Understanding disabling barriers: a fruitful partnership between Disability Studies and social practices? *Disability & Society,* 33(2):157-74.

Williams, V., Webb, J., Dowling, S., & Gall, M. (2019). Direct and indirect ways of managing epistemic asymmetries when eliciting memories. *Discourse Studies*, *21*(2), 199-215.

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