Title: ***"It's just so important that people's voices are heard.":*** **The Dementia Associate Panel**

ABSTRACT

Including the views and experiences of people living with dementia in research and wider decision making is vital. The impact for the subjective wellbeing of its members of an approach known as The Dementia Associate Panel (DAP) is explored. The panel, based on a social citizenship model, aimed to provide a platform to work with and hear the voices of people living with dementia in a region of England. A mixed method approach using semi-structured interviews, self-report questionnaires, and focus groups was adopted. There were 16 participants; six people living with dementia and ten care partners. Participant motivations to join the panel were based on a desire for individuals' voices and experiences to be heard. Following participation in the panel, participants reported experiencing belonging and purpose. Collective and personal contributions to the development of local health and care policies, education provision, research studies, and to raising general public awareness about dementia was beneficial to reported participant wellbeing. The DAP model has the potential to be developed and adapted when working with people living with dementia in different settings; at national or regional levels across the globe.

Key words: dementia, inclusion, involvement, user views

INTRODUCTION

‘Hearing’ the voices of people living with dementia has been acknowledged to be of paramount importance in shaping and developing future research, policy, and care practice (Bethell et al., 2018, Gove et al., 2018, Miah et al.,2019). People living with dementia no longer need to accept that their diagnosis of dementia means an immediate lack of independence and rights (Wiersma et al., 2016). Studies have identified that people living with dementia can actively contribute to and engage within their communities (Mockford et al., 2017) and this has been acknowledged in policy directives (Department of Health, 2012, 2015). Dementia Advocacy and Support Network International (DASNI) in the US argued that those conducting dementia related work should ensure that they included people living with dementia and adopted the tagline ‘nothing about us, without us’ (Clare, Rowlands and Quin, 2008). This approach has been adopted by others, for example, in the United Kingdom, The Dementia Engagement and Empowerment (DEEP) initiative aims to support groups to change and develop services and policies, using the strap line ‘nothing about us, without us’ demonstrating this ambition (Williamson, 2012). National collectives, such as Groups involving people living with dementia and their care partners in decision making exist throughout the world, for example, The Scottish Dementia Working Group, and Dementia Advocacy Canada. Dementia Alliance International is a key international association solely serving people living with dementia across the world, and has successfully argued for full inclusion (DAI, n.d). Such groups are driven by people living with dementia and challenge previous assumptions of passivity and lack of ability y (Bartlett, 2014). Social citizenship, positioning people living with dementia as empowered members of society who have the ability to contribute to research policy and practice, has become important in the dementia field (Bartlett and O’Connor, 2007) with Shakespeare, Zeilig, and Mittler (2019) highlighting the importance of considering people living with the condition as activists within society. Social citizenship models are argued to provide deeper insight into the lived experiences of dementia (Birt, Poland, Csipke and Charlesworth, 2017). Achieving social citizenship requires hearing the views and experiences of people living with dementia; that is, the stories and narratives of those living with dementia are included and recognised as important (Baldwin, 2008). Accordingly, the stories we tell, listen to, or reinforce can “empower and facilitate or to degrade, control or dominate another” (224). Baldwin argues that through our stories we can give voice to or silence others, thus allowing or denying people a legitimate place within society. Recognising and supporting relationships is one way to engage and empower those living with dementia to participate in social life and provide opportunities to achieve social citizenship (Keyes, Clark and Gibb, 2018). Ensuring that the narratives, or stories and experiences of those living with dementia (the person diagnosed and the care partner), are heard is key to challenging the dominant discourse that traditionally excludes the accounts of those with dementia (Baldwin, 2008), and in the process disallows opportunities for social citizenship and agency to occur. Creative approaches have evolved to address the challenge of narrative citizenship (Dupuis et al., 2016) demonstrating that with careful thought, planning, and acknowledgement of the social positioning of both the person with the diagnosis of dementia and their care partners, it is possible for those living with dementia to begin to reclaim the narrative of their lives. This is important as activating social citizenship is a challenge for those living with dementia, but it is crucial that people living with dementia play an active role in influencing policy and practice decisions that shape their lives (Brannelly, 2016, Kelly and Innes, 2012).

Empowering people living with dementia entails a “confidence building process whereby PWD are respected, have a voice and are heard, are involved in making decisions about their lives and have the opportunity to create change through access to appropriate resources” (McConnell et al., 2019, p. 1). This approach challenges previous assumptions of people living with dementia as incapable or unable to have their say and replaces it with the acknowledgement that hearing the ‘voice’ of this group is of paramount importance. The motivations of participatory approaches are increasingly popular, promoting the view that is “more consistent with the reality of many people with dementia as active, engaged and socially contributing to society” (Bartlett and Connor, 2007, p. 7).

Societal barriers that have limited inclusion in the past (Hackett, Steptoe, Cadar, and Fancour, 2019), alongside the nature of impairment that people with dementia experience, can place considerable demands on the individuals’ capacity to realise their maintained potential (Bartlett, 2014). In 2004, Innes, Archibald and Murphy’s edited volume was one of the first collections highlighting the impact of stigma, marginalisation, and social exclusion in dementia research, policy, and practice. It included many examples of how people living with dementia and their lived experiences had been marginalised. This marginalisation included lack of inclusion of people from minority ethnic groups already facing discrimination, people with dementia living in rural areas, and discussion of ‘taboo’ topics of sexuality or areas of experience that had been largely ignored, such as end of life care needs (Innes et al., 2004, 11-12). Although research and practice has developed in all areas in the 17 years since this collection, the stigma surrounding dementia globally (Hand, 2019) and the challenge of changing public perceptions (Reynolds, Innes, Poyner and Hambidge, 2017) persists. This is reinforced by Gilmour and Brannelly (2010) who point to the historical invisibility of people with dementia, their marginalisation in Western society, and the ways biomedical privileging of knowledge of dementia reinforces negative stereotypes within practice. This means that despite efforts of national bodies such as Alzheimer Disease International (2019) to raise awareness of stigma and draw attention to initiatives to tackle it, dementia remains a condition that is misunderstood by many - perpetuating stigma and the social exclusion of those with the diagnosis from all aspects of social life, including research.

Acknowledging the difficulties dominant discourses of dementia bring to activating citizenship for those living with dementia, Bartlett and O'Connor (2010) argue that to move beyond the limitations of conventional understandings of dementia and citizenship requires seeing citizenship as a process that: "involves justice, recognition of social positions and the upholding of personhood, rights and a fluid degree of responsibility for shaping events at a personal and societal level" (p. 37). People living with dementia can continue to meaningfully and actively participate in society although not all people receiving a diagnosis of dementia will become activists. Many people living with dementia will be managing other co-morbidities, be increasingly dependent on the support of others as they age with the condition, and/or not be inclined toward advocacy work. Less active 'citizens' will require the support of others to exercise their rights and social responsibilities and to continue contributing to their communities (Birt et al., 2017). It is important to acknowledge the vulnerabilities of people living with dementia whilst also recognising them as 'agentic'; that is, as having individual agency (Phinney Kelson, Baumbusch, O’Connor and Purves, 2016). The barriers to this inclusion are not only social but are also influenced by interpretations of the Helsinki declaration (World Medical Association, 2018) and ethical principles of autonomy, respect, beneficence, and justice. That is, it directly addresses the ethical advice/requirement around consent - which has largely been interpreted to mean that people with cognitive impairment are unable to understand the implications of research and participation, and thus provide informed consent.

It is within this space that dementia activist groups come to the fore, raising awareness and providing social structures enabling those living with dementia the right to continue to participate in spite of stigma or discrimination. Despite the increasing quantity of initiatives to promote the voice of people living with dementia, such as the Scottish Dementia Working Group, Dementia Advocacy Canada and Dementia Alliance International, the impact of groups and initiatives informed by a social citizenship approach are yet to be evaluated, representing a key gap in the literature (Phinney et al., 2016). An early exception to this is the work of Dupuis and colleagues (2012) who argued that “Listening and hearing the perspectives of persons with dementia is not enough. We must actively involve them in decision-making to the fullest of their abilities, and support their involvement using whatever means necessary” (p.433). They argue that key principles of Connecting and committing; Creating a safe space; Valuing diverse perspectives; Establishing and maintaining open communication; and Conducting regular critical reflection and dialogue are vital to achieving active involvement. Involvement activities are time consuming, require high levels of commitment from all involved, and are often in practice tokenised representatives on individual research advisory groups. The Dementia Associate

Panel aimed to overcome the latter and committed the time and energy of staff and DAP members to taking a new approach to promoting the voices of those living with dementia. In addition, little is known about the individual impact of being a member of an activist group and how this may relate to wellbeing for the person. This paper reports on a novel activist approach, known as the Dementia Associates Panel, and as such makes an important and timely contribution to the wider literature on the process and outcomes of dementia activist groups, informed by social citizenship principles for people living with dementia. The limited concerted efforts to create approaches to involve those living with dementia and their care partners means new approaches are needed; the DAP model offers an opportunity not just to inform research but also to reimagine the participation of people with dementia.

The Dementia Associates Panel Initiative

The DAP emerged as an initiative when a wide team conducting work in the dementia field at the University of Salford in the UK wished to develop existing user involvement approaches (Bartlett, 2014; Dupuis, et al., 2012, 2016) to guide and shape not just our research, but education and public engagement activities as well. Our team ran a variety of groups for people living with dementia and their care partners, including a café, two music groups, and a gardening group that were increasingly co-designed with attendees and facilitators. Over time, many of those attending these groups also expressed a wish to be involved in the wider activities of our staff group (Bowker et al., 2020)). The DAP was therefore developed over time as a way to actively involve people living with dementia and their care partners in the decision-making activities underpinning our academic work, including the groups we ran on campus for people living with dementia in the community. A 6-month (Sept 19 – Feb 19) consultation period was conducted with staff, people living with dementia and current and former care partners This resulted in Terms of Reference for the new Dementia Associate Panel being established and the recruitment of members to the Panel from existing attendees.

The Terms of Reference for the Panel agreed upon were:

1. Meetings will be held each month within the academic year (Sept – June).
2. Associates will be asked to commit themselves to the role for 12 months in the first instance.
3. We wish to have a panel of up to 20 individuals – we would aim to have 10 associates attend each meeting.
4. Lunch and travel expenses will be provided.

Associates will be involved in the work of the dementia institute by advising in the following key ways:

1. Advising on ideas, suggesting new topics and at times participating in the research undertaken by staff and doctoral students (proposed research and funded work).
2. Relevant content to educational programmes offered across the University.
3. Public engagement and community involvement activities.
4. Promotional work for the institute (e.g., newsletter, website, videos, interviews).
5. Fund raising for the activities run in the Hub [meeting venue].
6. A small sub group has been established, and will be chaired by an associate, to support the work of the institute in two ways: i. fund raising for Hub based activities; and ii. providing support to the hosting of events in the Hub.
7. Reviewing institute outputs (e.g., newsletters, bids, community-based information leaflets).

8. Other activities as required in line with Institute activities.

Practical issues to facilitate involvement in the meetings were identified and acted on. The two primary issues members initially raised were parking and food choices at lunch. The majority of members were able to travel to the meeting venue on their own via bus or car. For those who required it, taxis were arranged. Parking bays close to the meeting venue were negotiated with the University for reservation by our members (who did not have a disabled parking badge) in response to concerns about the time required to search for a space when busy and also to avoid using car parks that were further from the venue. Lunch was provided before each meeting commenced. Following feedback on the difficulty some members had with the catering team's choice of fillings for sandwiches and the inclusion of foods unsuitable for other conditions, for example diabetes (certain fruits and cakes) or arthritis (finger foods that were messy and difficult to eat), a meeting was held with catering staff and group members and a choice of menu items was agreed upon. This was a very important process for DAP members as they were actively involved in developing a menu that was suitable for not only cognitive issues, but also other health conditions.

The teams' community engagement officer facilitated each meeting with the support of the lead author and other team members as appropriate to the topics being discussed. Any queries/questions raised by the group were taken forward by the community engagement officer, with responses brought back to the group at the next meeting if possible. In this way, the Panel members were involved in a dialogue with the staff team. Members initially did not want an agenda in advance of the meeting, however over time members desired advance notice of who was going to be at the meeting (e.g., seeking advice on content of education programmes or a particular research study) and what the topics on the agenda would be. In response, an agenda and notes from the previous meeting were circulated via hard copy in the mail and electronic copies via email to accommodate different preferences. This was another important milestone for our members as their confidence grew in articulating their needs, suggesting alternatives, and the staff team's willingness to listen and act on their views about how they could participate fully. The Terms of Reference were revisited to check members were happy to continue working to these, and 'ground rules' were discussed when meetings became lively debates and individual members had aired differences of opinion. One member requested the use of a card she could raise in the air when she wished to speak, over time one or two other members also made use of these cards.

In addition to addressing the concerns and needs of members, the agenda for the meetings began to be actively decided by group members. When asked what topics/groups/other staff they would like to see on the agenda, local service providers were invited to come hear members' concerns about their experiences; senior colleagues within the University were approached for more involvement (e.g., expansion of the space allocated for our gardening group); and also requests were made to visit areas of the University (e.g., the Science Labs where basic science exploring dementia was underway and the skills labs where health programme students had classes). In these ways, the DAP evolved to address the concerns of our members.

The Panel was initially intended to advise on research, education, and public engagement activities at the University of Salford.. However, over time external researchers began to seek the input from panel members as advisors as well as participants in their research and towards the end of the research period, Panel members were active in suggesting research topics and were written into bids as named co-applicants or co-researchers, reflecting the process, over time, where members took ownership of future direction of work.. Panel members became members of other external advisory and advocacy groups. Members were invited speakers in their own right at events following others hearing them co-present with institute staff. The work of the panelevolved as the confidence of members increased and the skills, knowledge, and expertise of panel members were acknowledged, both by staff at the Institute, but also by external colleagues. In this way, we found a mechanism to achieve social citizenship principles through partnering with people living with dementia and their care partners in the decision-making discussions underpinning our academic work.

METHODS

A mixed methods approach, using interviews and focus groups, was adopted to capture the views of members before (month 1) and after (months 13-14) the study period. Self-reported questionnaires were used to capture the month-by-month views of participants at 12 meetings and the meeting minutes were analysed.

We aimed to answer the research question: What impact does membership of the Dementia Associate Panel have for people living with dementia and their care partners? Methods included semi-structured interviews, self-report questionnaires, semi-structured focus groups, and documentary analysis of meeting minutes. Involving people with experience of living with dementia in the research process has been shown to increase the quality of research findings through improving internal validity and incorporating multiple perspectives (Stevenson, Savage and Taylor, 2017).

We recruited Panel members from our existing database of people living with dementia and care partners attending groups at the University. Due to the social and peer support engendered by the groups, care partners continued attending groups after their relatives died or went into long stay care provision, and their experiences often benefitted new members who were at an earlier point in supporting a person living with dementia. All panel members were invited to participate in the study and were given information sheets and a verbal introduction to the study, and a signed consent form was received from all participants. No further incentives were offered for research participation, although Panel members received lunch, travel arrangements (e.g., taxis), and two annual ‘thank you outings’, selected on the basis of group discussions (e.g., afternoon tea at an historic venue, a trip to the theatre). Sixteen of the 17 regular members of the panel agreed to participate in the research; six people living with dementia (PLWD), three males and three females between 62 and 87 years old; six current care partners (CP), one male and five females ranging in age from 50 to 79 years old; and four former care partners (FCP), one male and three female between the ages of 78 and 81 who were primarily spouses or family members. Participants with dementia all self-identified as having some form of dementia and had undergone a diagnostic process.

Full ethics approval was obtained from the University of Salford ethics panel (approval number: HSR1718-026) prior to recruiting participants. All respondents were able to give informed written consent and we followed the process consent method detailed by Dewing (2008), including ensuring ongoing consent was obtained at each meeting. One way this was achieved was when participants were reminded at each meeting that they were involved in a research study and consented on a meeting-by-meeting basis by completing the self-report questionnaires.

The study took place over a 14-month period with data collected at three time points to track experiences of being a member of the Dementia Associates Panel over time as well as to ascertain motivation and expectations at the outset compared to actual experiences following participation. Following 10 initial semi-structured interviews (4 dyad and 8 individual), the DAP met once a month in 'The Hub', a space designed with people living with dementia. The real time impact of being a member of the DAP was captured using self-report questionnaires at the end of each meeting. The questionnaires (table 3) allowed participants to indicate whether the meeting effectively supported their contribution of views and ideas, and whether these perspectives and suggestions were actioned. The same questionnaire was used after each meeting. The questionnaires themselves were designed prior to using to ensure everyone understood the wording and how to complete them. An iterative process was followed where new versions were developed based on group discussions until a consensus was reached; for example, the visual (faces) were particularly liked by those with dementia but not by care partners. Meeting minutes were taken and analysed. Following the 14-month period, both interviews and focus groups were used to accommodate the preferences of participants, all of whom participated in data collection at all time periods. Two wished to talk as a group about their experiences of the Panel at 'the Hub', while one preferred to talk 1-1 in their own home. Seven 1-1 qualitative semi-structured interviews and 1 focus group with 2 participants were conducted each lasting up to 1 hour.

Data from the interviews and focus groups were audio recorded and transcribed verbatim and analysed using a six-step thematic approach (Braun and Clarke, 2006), incorporating inductive and deductive techniques guided by the research questions but also by the information shared by participants, to capture the subjective lived experiences of participants. Data from the self-report questionnaires were entered into excel and were also analysed thematically alongside the meeting minutes. Codes were generated for each data source and then corroborated by another second member of the team. Initial data analysis and report writing was shared with DAP members, who agreed the findings reflected both their collective and individual experiences. This analytical process enabled all data to be analysed using the thematic framework generated from phase 1 interview data. Principles of social inclusion and social citizenship not only informed the DAP initiative, but also how we approached our data analysis. The COREQ guidelines, a set of principles to present qualitative data, (Tong, Sainsbury and Craig, 2007) were consulted in relation to the reporting of this study.

RESULTS

Three thematic findings include i) the motivations for joining the DAP, ii) participation in the panel promoting a sense of belonging and purpose, and iii) the individual and collective benefits of involvement.

Motivations for joining the Dementia Associate Panel

Four thematic areas were identified in relation to the motivations participants had for joining DAP. All participants reported that their wellbeing could be increased through **‘Sharing Lived Experiences’** illustrating the positive ways that people seek support and understanding and how this can be reciprocal, having a positive impact on wellbeing. **Encouraging Voices** was stressed by all participants as crucial to being seen as experts of the condition. All participants considered that **Contributing to Change** was of paramount importance. '**Nowhere to Turn'** describes care partners reporting the negative impact on their wellbeing following the diagnosis received by their loved one, as a result of a lack of external support and knowledge of what to do. For participants living with dementia, a personal loss of independence and confidence was reported to be most detrimental to their wellbeing. This reflects the confusion and the overwhelming sense of dislocation that might accompany a diagnosis and the lack of sign posting to appropriate (or accepted) supports for either the care partner or the person in receipt of the diagnosis.

Sharing Lived Experiences

Participants considered sharing their lived experience of dementia as positively impacting their wellbeing and the wellbeing of others. For care partners, sharing their experiences with others is reciprocal with both parties gaining from knowledge and support:

> We really want to hear the voice of carers and the voice of people living with dementia. It's quite hard to find opportunities or be plugged into something that starts to make a difference but once you find them you want to make sure you stay there (Zara).

> It's a bunch of people who support each other, all have basically the same goal in life and that brings you closer together, that you can talk about things and it seems to be easier to talk to people who have experienced the same (Oliver).

For participants living with dementia, it is important to be able to share experiences with other people living with the condition as they understand keenly.

> If it was something I could actually talk about, something I had experience on, something I was annoyed at… I think a lot of people don't understand what me does and what things I've done in the past (Eric).

> So what I like about coming here is that people will actually ask us for comments, our opinions, it's a two-way street (Alice).

A sense of having one's life history, skills, and experiences stripped away is a major incentive for people to share their lived experiences. Joining DAP enabled participants to be heard and to feel understood and illustrates the positive ways that people may seek support and understanding, as well as how this can be reciprocal, having a positive impact on both their sense of self and wellbeing.

Encouraging Voices

All participants attached importance to being heard. For example, care partners suggest "I think that's key, to actually be listened to and that's by everybody…. because we've lived that experience or we're living the experience and that is the best thing ever…" (Laura). For participants living with dementia, the opportunity to be heard can go some way toward dispelling stigma and negative assumptions around dementia: "It's just so important that people's voices are heard. Just to know that we've all got a voice, and we are being heard" (Elliott).

All participants stressed the importance of having a ‘voice’ and being listened to as experts of the condition. Being heard within research and broader society were all reported as important for raising awareness around dementia.

Contributing to Change

Participants believed that sharing experiences can raise awareness and challenge societal misconceptions around dementia. For example, “I think the whole country should know about dementia…” (Alice) and “I just think we are a group of people trying to change the way people think about dementia. It’s really about getting past what I want for myself and thinking what I can achieve for others” (Yvonne).

For all participants, contributing to change was of clear and distinct importance. Having a voice, raising awareness, and creating change were also reported as factors enabling participants to have a purpose.

Nowhere to Turn

Participants described their reactions to receiving a diagnosis of dementia and the many ways this negatively impacted their wellbeing. For those participants who were care partners, the notion of not knowing where to turn came through powerfully, “There was nowhere to go, nowhere to ask advice; you were given the diagnosis, we’ll see you in six weeks, and that was it basically, we were on our own. You don’t know where to turn to, you don’t know who you can talk to” (Helen).

This lack of support and sense of isolation can lead to fear and negatively impact the ability of the care partner to provide support and ensure their personal wellbeing.

For participants with a diagnosis of dementia, the impact on wellbeing was more about personal loss of independence and confidence rather than a lack of places to turn, "I lost my independence really, but I suppose the worst thing was the income from my job, really… I mean, I've got my family but it's not the same" (Yvonne)**.**

A lack of support for either the care partner and/or the person living with dementia can have a profound effect on the ability of both to process the information given, to cope, and to work out what they can positively and actively do to address the shock and impact of what dementia means for their immediate and future lives.

Experiences of the DAP meetings

Overall participants' experiences of the DAP meetings were positive. Related to the *DAP meeting format*, that is, the structure, content, and process of the meetings (such as raising issues), was positive, however participants wanted to receive more feedback from visitors who had attended DAP meetings and received their help and advice. Participants felt that the group was inclusive and that they could express their opinions freely and without judgement. Participants reported a range of '*Emotional Responses'*. This included experience of conflicting opinions, positive responses to meetings, and feelings of inclusion and being valued. The DAP was a positive emotional experience. In particular, participants felt included and valued within the group and enjoyed learning about new activities and research. The experience of conflicting opinions recounted by participants demonstrates the diverse range of opinions and ideas expressed by DAP members. For example, differences in opinions between care partners and people living with dementia were reported within the questionnaires. Care partners stated that the paperwork was too complex for people living with dementia. However, this was not consistent with the view of participants living with dementia as they were happy with the paperwork and how the information was being communicated. This is an important feature of DAP as it demonstrates that participants felt empowered and able to promote their varying opinions and views.

DAP meeting format: The structure, content, and process of the meetings was important to participants. This included opportunities to raise issues that were of interest to them, opportunities for feedback on issues and concerns previously raised, and finally finding ways to help visitors to DAP present their materials in more understandable formats.

Raising issues: Within the questionnaire, participants were asked ‘Did the meeting give you the opportunity to raise issues of interest to you?’ Findings calculated from an overall average of the fourteen-month period demonstrate that over three quarters of associates felt that they had the opportunity to raise an issue of their choosing.

Feedback: Five participants expressed their frustrations at sharing advice and ideas and then not receiving information about the outcome. For example, “Yeah, I think we’re listened to, but we don’t get a lot of feedback of what we’ve done. Sometimes we do. But not on everything…... And it’s important, especially when the input that you have…update would be nice….” (Yvonne) and “We want them to come back. We’ve given our time to them. Is it not only right that they should give a little time back to us to tell us how they've developed it?...... We want to know whether we're wasting our time" (Sally).

Less positive responses related to the number of items discussed in a particular meeting, "less items for discussion so that specific information could be absorbed" (Sally), and the response from external people who had come to talk to the DAP members "use plain speaking language and not so much academic jargon" (Mary). On occasions where less positive feedback was received, DAP facilitators immediately acknowledged concerns and responded by ensuring that all information for subsequent meetings was clear, appropriate and inclusive of people living with dementia. The positive effect of this was seen in the subsequent DAP meeting when all participants stated that they felt 'very happy' or 'happy' after the meeting.

Over the 14-month period, concerns around difficulties in understanding the information within the meetings emerged. After one meeting a participant stated, "My dementia leaves me more unable to understand and keep with the pace" (Eric).

It is evident that the DAP meetings were experienced positively and that the venue and refreshments helped create a positive atmosphere, demonstrated by comments such as "Lunch and refreshments were very good" (FC02). However, there was also room for improvement. Findings show that the DAP was successful in enabling and supporting participants to share their opinions and raise issues, something that can create feelings of empowerment and sense of purpose; and that DAP membership enabled participants to become involved in a range of community engagement and awareness activities.

Emotional Responses

DAP members experienced a range of emotional responses in themselves and in other members. This included conflicting opinions, feeling positive about participation, and feelings of inclusion and being valued.

Conflicting Opinions: Participants did not always agree with each other, decisions made by others, or the noise level, "too many people talking at once so just became noise" (Laura). Differences in opinions between care partners and people living with dementia were found, with care partners stating that the paperwork was too complex for people living with dementia. However, this was not consistent with the view of participants living with dementia as they were happy with the paperwork and how the information was communicated.

Feeling positive about participation: Overall, participants felt positive about the DAP. After each meeting they were asked to complete a self-report questionnaire. Over the duration of the study, with seventy-five percent reporting high or very high levels of enjoyment. Seventy-seven percent of responses agreed that the meeting had met their expectations, and over half felt very confident or confident that the issues discussed would lead to change, with around a quarter confident that the meeting would lead to change.

When asked if they would change anything about DAP, participants stated, "not sure it needed improvement" (Yvonne) or "the meeting was well organised even though there were a number of associates present” (Laura). Enjoyment was common, for example, “Enjoyed the meeting and listening to the issues raised” (Norman).

Inclusion and feeling valued: A key finding was the sense of social inclusion and value participating in DAP brought to participants: “Being involved with all of the discussions” (Norman and Laura) and “Discussions were appropriate, and everybody's views accepted (Yvonne). This feeling of inclusion and being valued was imperative within the group and findings from the questionnaire show that associates felt empowered to promote their voice and share their opinions: “Able to speak freely and have my opinions taken seriously” (Ellie) and “It was a full and engaged meeting that actually allowed for people’s opinions to be heard” (Laura).

Given the motivations for participating in DAP reported under ‘nowhere to turn’ above, the experience of being involved in this purposely inclusive approach offered participants the opportunity to share their views and experiences in a supportive environment where everyone listened to one another, and differences in opinion were tolerated and respected. Individual members felt included in the group that actively promoted hearing each member’s views on a range of complex issues, from research, to education and how to raise awareness of dementia via public engagement activities, and perhaps most importantly where members could see action as a result of sharing their views and ideas.

Wider impact of DAP membership

Our findings demonstrate that DAP membership encouraged participants to become involved in a range of further events and research and, as such, led to wider impact for individual participants, and also for the collective as they had worked on particular projects together. Thus, being included in DAP led to further social inclusion and involvement in wider societal events and initiatives.

Feelings of confidence, having a sense of purpose and sharing knowledge were key impacts reported. For those participants who are or were care partners, the formal and more political nature of the meetings was something they enjoyed. For example, “But I think for what it started off as and what it’s now become again it has really progressed, and it is more like the political arm…. a lot more people being able to give their points of view without it descending into an almighty row” (Ellie) and “The Associates are there as a group to help put into action or to advise more official bodies what dementia needs and what support it needs”Sally).

Particularly those who were living with dementia, it was apparent that membership had provided them with a sense of purpose and feelings of belonging. In response to being asked if they found Dementia Associates meaningful, Norman responded… “Well, yes, it is.” When asked if the benefits from the meetings were reciprocal, s/he replied: “I feel wanted…… I just enjoy coming here.” This was a particularly poignant response as his/ communication was compromised. When asked if he felt a sense of purpose as a DAP member, one man responded: “Oh yes, of course it does, otherwise I wouldn’t come, simple ……I’m just really pleased that somebody’s listening” (Eric).

Several participants described how DAP membership had enabled them to feel more confident and share their opinions to wider audiences.

> It’s helped me to have more confidence to stand up now and speak at different conferences so being a Dementia Associate has helped me to stand up, face people, talk about it, yes. This has given me a voice. At one time I would have sat back reluctant to say anything, to voice anything. I don’t feel that way now (David).

DAP membership promoted a sense of confidence and purpose for participants. Having the self-assurance to share their voice, enabled participants to engage in several activities to influence change: “Yes, you have to keep on talking, and eventually people either get bored of it or think, oh I suppose you’re right” (Eric) and “Pushing for change, yeah. I agree with that, finding new things, you know, to do which is important because it stimulates the mind, which is a very important thing in my opinion with dementia” (Oliver).

Collective impact related to involvement in education and awareness raising activities. The majority of participant’s acknowledged a passion to educate and inform others:

> To be able to educate, because that’s what I like about being an associate…to reduce the stigma, to show people, look, people have got a life post dementia, that they can still be part of society and to be a wider part of the community... (Laura)

For participants, it was also important to engage in wider public engagement events to promote research and education: “It’s helped me to go more into helping research through the university” (Sally).

Participants generally felt that their participation in DAP had helped them to become involved in research (59%), community engagement (59%), awareness raising (63%), education (51%), and additional activities (84%).

In response to researchers presenting their work to the panel, one participant responded that they had enjoyed “Learning about the new research bid” and “making new connections” (Zara). For community engagement events participants helped plan, comments included “enjoyed the discussions regarding the conference” (Tina) and “the conference planning was interesting” (Ellie). A range of public awareness events were developed and facilitated by participants. For example, two participants presented at a National conference where over one hundred people attended their talk, which was reported as an empowering and affirming experience. Involvement in education provision had been achieved in a variety of ways, including talking directly to students and participating in a user and carer committee supporting educational activities.

Thus, the initiative promoted both individual and collective involvement not only in the DAP meetings themselves but in broader areas of activity. Participants expressed a desire to continue with this work and to include and involve more people living with dementia in the future, “This hub should be buzzing in years to come with people with dementia ’cause still we’re not getting through to all these people who have got dementia” (Yvonne). This is an important observation as our sample size of 16 participants could be considered small, however, this was an optimal number to promote inclusion and involvement in the Panel meetings, and this was a bespoke initiative to promote active involvement of people living with dementia and their care partners.

DISCUSSION

This study explored the impact of an approach known as The Dementia Associate Panel (DAP) for the wellbeing of its members. The panel, based on a social citizenship model, aimed to provide a platform to work with and hear from people living with dementia in a region of England. The principles of social citizenship have been well documented in the literature and our study shows how it is possible to document the narratives of those living with dementia and their care partners' experiences. This was achieved by participating in a Panel, co-designed with participants, who wished to be actively involved in decision-making processes underpinning academic activities that in turn help to influence policy and practice (Brannelly, 2016; Dupuis et al., 2012; Kelly and Innes, 2012). In many ways, DAP members could be seen to be activists (Bartlett, 2014) through their participation in a group not only to join but to co-design and complete the Panel's work. Participating in the DAP was a positive experience and our findings demonstrate that participants felt included and a sense of purpose. This echoes previous research where participating within similar groups were liberating, empowering, and confidence building (Dupuis et al., 2012; Keyes et al., 2016) as well as providing opportunities for growth, change, and development (Bartlett and Connor, 2007).

Nevertheless, to understand the true impact of membership, it is important to state that at the start of the 14-month period, ‘nowhere to turn’ was a dominant theme. This echoes the reasons people living with dementia join groups (c.f. Bartlett’s 2014 activists and Dupuis et al.’s 2012 *A Changing Melody* group). Feelings of isolation and lack of support were particularly prevalent for participants who were either a care partner or former care partner of a person living with dementia. For people living with the condition, feelings of isolation were associated with the loss of independence and confidence caused by their condition. This is often the reality of many receiving a diagnosis a dementia who report a lack of autonomy and decreased interest in social activity (Graff et al, 2008), with reduced social contact having a negative impact upon wellbeing (van der Wardt et al., 2012).

Participants reported that the DAP meetings enabled them to access a reciprocal relationship with other members through sharing experiences and giving and receiving support. Hearing the voices of people living with dementia is important as it enables lived experiences to be shared and has the potential for influencing outcomes through sharing sincere first-hand accounts of life with dementia (Littlechild et al., 2015). Dupuis et al.’s (2012) finding that working in partnership ‘re-abled’ those with dementia to actively participate and be involved in decision making resonates with our data.

A wish to advocate for change was a prominent finding, with participants voicing their passion for influencing dementia care, and it was apparent that the meetings enabled them to promote their voice and prompt change in a variety of ways. Initiatives like the DAP are important as they provide a deeper understanding of different service insufficiencies that may not normally be acknowledged (Mayrhofer et al., 2017) and provide a way to operationalise Baldwin’s (2008) narrative citizenship through ensuring the accounts and stories of people living with dementia are not only heard (Brannelly, 2016) but acted upon (Dupuis et al., 2012, 2016). The unique benefits of DAP membership relate to the situational context of the institution and work of the team hosting DAP. We were able to provide a forum for service providers, policy makers, and researchers external to our institution to come to the panel as a forum to consult an established group who were able to articulate their views and opinions clearly within the context of their lived experiences and personal narratives.

Our findings demonstrate that participants wanted the meetings to be a platform for an activist initiative whereby they could make a wider impact and influence dementia care. The official nature and structure of the DAP was described by participants as a positive attribute. They felt that the formal nature of the meetings promoted the political ambitions of the group and allowed for clear agendas to be developed into how members could contribute and influence change. The formal nature of the DAP gave participants confidence to share their opinions, as they felt that they would be listened to. In this way, Baldwin’s (2008) narrative citizenship concept was at the centre of DAP activities. Our findings concur with a position paper arguing that creating feelings of empowerment for those involved whilst also tackling issues of anticipated hierarchy is necessary to promote change (Gove et al., 2018), and that prioritising the personal narratives of group members provided a platform to promote changes at practice and policy levels advocated by others (Brannelly, 2016; Kelly and Innes, 2012).

It was evident that participants valued their DAP membership and how they were supported to engage in a range of different activities and research. This is consistent with a Social Citizenship approach that highlights the importance of people living with dementia as active and engaging citizens who contribute to society (Bartlett and Connor, 2007), and this is achieved when academics work alongside and in partnership with people living with dementia, such as in Dupuis et al.'s (2012) authentic partnership model work. It is also important to highlight that participants were pleased that researchers sought their advice on matters. This again promoted feelings of purpose and inclusion for participants and fulfilled their ambitions of influencing dementia care, policy, and research. Providing lunch and transport to attend (if needed) were experienced favourably by participants; these are important factors to support the engagement of people living with dementia in user-led partnerships (Novek and Wilkinson, 2019).

Our findings demonstrate participants' passion for education and sharing of knowledge, echoing research demonstrating that the wellbeing of participants living with dementia and care partners is heightened when researchers create respectful and mutually reciprocal relationships (Dupuis et al., 2012; Hellström et al., 2007; Novek and Wilkinson, 2019). This is evident that participants felt empowered through engaging in academic research and working alongside researchers. For example, many discussed their positive experiences of collaborating with academics to write a peer reviewed journal paper (Bowker et al., 2020) and also a book (Innes, Calvert and Bowker, 2020). Many also enjoyed their involvement in developing the nursing student curriculum. They appreciated disseminating their knowledge to wider audiences through conferences and academic papers, which echoes the findings reported by Dupuis et al. (2012) and Bartlett (2014). Findings demonstrate that participation in DAP was important to individual wellbeing and collective ambitions of creating a wider impact echoing the findings of Beard and Fox (2008) who reported a sense of belonging and usefulness accompanying membership of support groups. Findings illustrated that overall, attending the monthly meetings provided them with numerous positive experiences. Although participants voiced their feelings of loss and isolation at the beginning of the 14-month research period, by the end, participants described their feelings of purpose and belonging. It can therefore be suggested that DAP contributed to developing individual and collective wellbeing in similar ways to those reported in Canadian research (Dupuis et al., 2012).

Participants were passionate about creating change and were keen to participate and get involved in opportunities that came their way. Findings demonstrate that the DAP provided a platform to promote their voice and influence dementia care practices and policy regionally as well as research and education provision. Participants reported feeling empowered through the DAP and this helped to both fulfil their own personal needs while facilitating their wider ambitions of contributing to change. The DAP therefore not only provides activities that promote peer support for participants but also a forum for advocacy and change, not just sharing and reaffirmation.

While participants' experiences were generally positive, concerns were expressed, namely a lack of feedback from students and staff who sought advice from the DAP. Brett et al. (2017) provides a deeper insight into the possible causes of tension explaining that a conflict can develop between researchers and user-engagement groups as assumptions can be made when conducting research that do not align with the needs and ambitions of group members. Participatory approaches designed to address concerns and promote change in dementia research are not always easy to manage or achieve (Hicks, Innes and Nyman, 2020; Dupuis et al., 2016). However, through addressing issues relating to feedback, participants highlighted that feelings of personal efficacy could be addressed by developing ideas based on feedback to fulfil their ambitions of contributing to change.

Those living with dementia reported that at times they had a lack of understanding during the meetings, largely related to verbal communication being conveyed too quickly by visitors to the DAP and also difficulties in understanding some written paperwork, which was addressed by facilitators. Also, care partners sometimes felt that the information was too complex for people living with dementia, yet this was not consistent with feedback from those who were living with dementia. It has been suggested that to achieve ‘social citizenship’, some form of separation from care partners may be required (Wiersma et al., 2016), possibly due to the perspectives of the person and the carer partner not always corresponding, each having very different and sometimes inconsistent experiences of the condition (Beard et al., 2012). The DAP, as with the reported findings of the authentic partnership approach (Dupuis et al., 2012), enabled participants to make collective and personal contributions to the development of local health and care policies, education provision, research studies, and contributing to raising general public awareness about dementia and was beneficial to reported participant wellbeing. In this way, the DAP created a unique and safe space for people living with dementia and care partners to come together, working within co-created Terms of Reference, setting the agenda for the work the panel collectively agreed to undertake that evolved over time as the confidence and skills of the individuals and collective grew and developed. Our study demonstrates principles of social citizenship in action and the benefits derived by participants in DAP.

Conclusions

The creation of the Dementia Associates Panel required the ‘ownership’ or ‘buy-in’ of people living with dementia and care partners (current and former). A social citizenship model led to participants reporting a sense of empowerment to share their views that brought personal fulfilment and also collective action as they worked together to promote change. The limited concerted efforts to create approaches to involve those living with dementia and their care partners renders a space where new approaches are needed. The DAP model offers an opportunity not just to inform research, but also to reimagine the participation of people with dementia.

Before joining DAP, participants felt isolated and had ‘nowhere to turn’ and by the end of the study, they spoke animatedly about having a sense of purpose and feeling included and valued. This is similar to the findings of other initiatives designed to promote partnership working (Bartlett, 2014; Dupuis et al., 2012). The integrated approach of DAP provided participants with numerous opportunities to engage in research, education, public awareness and community engagement activities and supported participants’ ambition of creating a wider impact. Due to the complexities of the condition that may limit the time a person may be able to independently advocate their ambitions and needs, it can be challenging to support a person living with dementia to engage in activities enabling personal and collective narratives to be heard, listened to and acted on (Shakespeare et al., 2019). An ongoing challenge is how to address the stigma and misconceptions that surround dementia, that contribute to a focus on the loss of skills rather than a focus on enhancing and retaining abilities (Bartlett, 2014). This challenge is relevant to how to recruit and support membership of individuals to groups, such as the DAP, that aim to promote partnership and involvement in decision-making. However, the benefits of doing so in terms of the wellbeing of individuals and the contribution to future knowledge makes it, in our view, an imperative well worth the risk.

Participants stressed the importance of recruiting further members to DAP to sustain and develop the group. DAP offers a model of involvement and inclusion based on a social citizenship model that could be applied to other settings and other regions/countries concerned with hearing the lived experiences and the implications this has for policy, research, or practice. Involving people living with dementia and their care partners is not only desirable, but also critical to the development of impactful and meaningful research and other activities that can promote awareness and improvements in dementia support and services. The DAP model provides an example of a group designed to promote inclusion and involvement in research, education and public engagement activities and has the potential to be adapted to other settings. Further research is required to enhance the generalisability of this approach as our work is in one region in England and with a sample of 16 panel members.

However, the findings from our research suggest that the following are important considerations for those facilitating groups such as the DAP: Facilitators should consider how best to provide people living with dementia and care partners with regular feedback regarding the progress of their ideas and recommendations. The structure and chairing of meetings need to ensure that any views or issues are carried forward until they have been adequately addressed. This not only supports feelings of personal efficacy but allows a structure to develop and support ambitions of change. Practical considerations for other facilitators include considering the layout of the room before meetings commence to ensure that it encourages conversation between group members. Information clearly communicated both verbally and in writing through meeting agendas enables inclusion of both people living with dementia and care partners and different communication preferences. We also recommend that groups ensure that people living with dementia are adequately represented and are not over-powered by care partners. People living with dementia should be supported to share their views and contribute to decision making. Groups such as DAP must promote and acknowledge the views of people living with dementia and care partners to support and influence future research, care and policy. The first-hand lived experiences of dementia are essential to identifying the salient issues. Creating forums to enable such discussions is an important first step to achieving the social citizenship that is often denied to those living with dementia.

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References

Alzheimer’s Disease International. (2019). *World Alzheimer Report 2019: Attitudes to dementia*. London: Alzheimer’s Disease International. Retrieved from https://www.alzint.org/u/WorldAlzheimerReport2019.pdf accessed 3 August 2021

Baldwin, C. (2008). Narrative(,) citizenship and dementia: The personal and the political. *Journal of Aging Studies, 22*, 222–228. https://doi.org/10.1016/j.jaging.2007.04.002

Bartlett, R. (2014). Citizenship in action: the lived experiences of citizens with dementia who campaign for social change. *Disability and Society*, *29*(8), 1291–1304. https://doi.org/10.1080/09687599.2014.924905

Bartlett, R., and O’Connor, D. (2010). *Broadening the dementia debate: Towards social citizenship*. Bristol, England: The Policy Press.

Bartlett, R, and Connor, D. O. (2007). From personhood to citizenship: Broadening the lens for dementia practice and research. *Journal of Aging Studies*, *21*, 107–118. https://doi.org/10.1016/j.jaging.2006.09.002

Beard, R. L., Sakhtah, S., Imse, V. and Galvin, J. E. (2012). Negotiating the joint career: couples adapting to Alzheimer’s and aging in place. *Journal of Aging Research*, 797023. https://doi.org/10.1155/2012/797023

Beard, R.L. and Fox, P.J. (2008). Resisting social disenfranchisement: negotiating collective identities and everyday life with memory loss. *Social Science and Medicine*. *66*(7),1509-20. doi: 10.1016/j.socscimed.2007.12.024.

Bethell, J., Pringle, D., Chambers, L.W., Cohen, C., Commisso, E., Cowan, K., Fehr, P., Laupacis, A., Szeto, P. and McGilton, K.S. (2018). Patient and Public Involvement in Identifying Dementia Research Priorities. *Journal of the American Geriatrics Society* 66(8) 1608-1612. https://doi.org/10.1111/jgs.15453

Birt, L., Poland, F., Csipke, E., and Charlesworth, G. (2017). Shifting dementia discourses from deficit to active citizenship. *Sociology of Health and Illness*, *39*(2), 199–211. https://doi.org/10.1111/1467-9566.12530

Bowker, R., Calvert, L., Allcroft, F., Bowker, G., Foy, P., Gandy, J., Jones, S., Bushell, S., Clark, A and Innes, A. **(**2020) ‘Our voice started off as a whisper and now it is a great big roar’: The Salford Dementia Associate Panel as a model of involvement in research activities. *Dementia*. 19(1), 18-26. https://doi:10.1177/1471301219874225

Brannelly, T. (2016). Citizenship and people living with dementia: A case for the ethics of care. *Dementia*, *15*(3), 304-314. https://doi.org/10.1177/1471301216639463

Braun, V., and Clarke, V. (2006). Qualitative Research in Psychology Using thematic analysis in psychology Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. doi: 10.1191/1478088706qp063oa

Brett, J., Staniszewska, S., Simera, I., Seers, K., Mockford, C., Goodlad, S., Altman, D., Moher, D., Barber, R., Dengeri, S., Entwistle, A.R., Littlejohns, P., Morris, C., Suleman, R., Thomas, V and Tysall, C. (2017). Reaching consensus on reporting patient and public involvement (PPI) in research: Methods and lessons learned from the development of reporting guidelines. *BMJ Open*, *7*(10), 1–10. https://doi.org/10.1136/bmjopen-2017-016948

Clare, L., Rowlands, J. M., and Quin, R. (2008). Collective strength: The impact of developing a shared social identity in early-stage dementia. *Dementia*, *7*(1), 9-30. doi:10.1177/1471301207085365

Dementia Alliance International (n.d.) *Our Core Beliefs* Retrieved from https://www.dementiaallianceinternational.org/about-dai/core-beliefs/ accessed 3 August 2021

Department of Health. (2012). *Prime Minister's challenge on dementia*. London. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215101/dh_133176.pdf accessed 3 August 2021

Department of Health. (2015). *Prime Minister's challenge on dementia 2020*. London. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf accessed 3 August 2021

Dewing, J. (2008). Process consent and research with older persons living with dementia. *Research Ethics Review*. *4*(2), 59–64. https://core.ac.uk/download/pdf/159483529.pdf

Dupuis, S.L., Kontos, P., Mitchell, G., Jonas-Simpson, C., and Gray, J. (2016). Re-claiming citizenship through the arts**.** *Dementia*, *15*(3), 358-380. Doi:10.1177/1471301216637206

Dupuis, S.L., Gillies, J., Carson, J., Whyte, C., Genoe, R., Loiselle, L., and Sadler, L. (2012). Moving beyond patient and client approaches: Mobilizing 'authentic partnerships' in dementia care, support and services. *Dementia*. *11*(4), 427-452. doi:10.1177/1471301211421063

Gilmour, J. and Brannelly, T. (2010) Representations of people with dementia–subaltern, person, citizen. *Nursing Inquiry* 17, 240– 247.

Gove, D., Diaz-Ponce, A., Georges, J., Moniz-Cook, E., Mountain, G., Chattat, R., and Øksnebjerg, L. (2018). Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement). *Aging and Mental Health*, *22*(6), 723–729. https://doi.org/10.1080/13607863.2017.1317334

Graff, M.J.L., Adang, E.M.M., Vernooij-Dassen, M.J.M., Dekker, J., Jönsson, L., Thijssen, M., Hoefnagels, W.H.L. and Rikkert, M.G. (2008). Community occupational therapy for older patients with dementia and their care givers: cost effectiveness study. *BMJ (Clinical Research Ed.), 336*(7636), 134–138. https://doi.org/10.1136/bmj.39408.481898.BE

Hackett, RA., Steptoe, A., Cadar, D., Fancourt, D. (2019). Social engagement before and after dementia diagnosis in the English Longitudinal Study of Ageing. PLoS ONE 14(8): e0220195. https://doi.org/10.1371/journal.pone.0220195

Hand, M.D. (2019). Every Three Seconds: A Review of an Innovative Documentary on Research and Stigma Surrounding Dementia Across the Globe. *Journal Gerontological Social Work*. *62*(3), 369-373. doi: 10.1080/01634372.2018.1541951

Hellström, I., Nolan, M., Nordenfelt, L., and Lundh, U. (2007). Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics*, *14*(5), 608–619. https://doi.org/10.1177/0969733007080206

Hicks, B., Innes, A. and Nyman, S. (2020). Exploring the 'active mechanisms' for engaging rural-dwelling older men with dementia in a community technological initiative. *Ageing and Society, 40*(9), 1906-1938.https://doi.org/10.1017/S0144686X19000357

Innes, A., Archibald, C. and Murphy, C. (2004) "Introduction" in Innes, A., Archibald, C. and Murphy, C. (Eds). *Dementia and Social Inclusion: Marginalised groups and marginalised areas of dementia research, care and practice*. (Pp 11-17). London: Jessica Kingsley

Innes, A., Bowker, G. and Calvert, L. (2020) *Dementia: The Basics*. London: Routledge.

Kelly, F. and Innes, A. (2012). Human rights, citizenship and dementia care nursing. *International Journal of Older People Nursing*, *8*, 61-70. https://doi/10.1111/j.1748-3743.2011.00308.x

Keyes, S.E., Clarke, C.L. and Gibb, C.E. (2019). Living with dementia, interdependence and citizenship: narratives of everyday decision-making, *Disability & Society*, 34:2, 296-319, doi:10.1080/09687599.2018.1528970

Keyes, S. E., Clarke, C. L., Wilkinson, H., Alexjuk, E. J., Wilcockson, J., Robinson, L., Reynolds, J., McClelland, S., Corner, L. and Cattan, M. (2016). “We’re all thrown in the same boat … ”: A qualitative analysis of peer support in dementia care. *Dementia*, *15*(4), 560–577. https://doi.org/10.1177/1471301214529575

Littlechild, R., Tanner, D. and Hall, K. (2015). Co-research with older people: Perspectives on impact. *Qualitative Social Work*, 14(1), 18-35. https://doi: 10.1177/1473325014556791

Mayrhofer, A. M., Mathie, E., McKeown, J., Goodman, C., Irvine, L. and Hall, N. M. W. (2017). Young onset dementia: Public involvement in co-designing community-based support. *Aging and Mental Health*, *22*(8), 933–941. https://doi.org/10.1080/13607863.2017.1334038

Miah, J., Dawes, P., Edwards, S., Leroi, I., Starling, B. and Parsons, S. (2019). Patient and public involvement in dementia research in the European Union: a scoping review. *BMC Geriatrics,* 19:220. https://doi.org/10.1186/s12877-019-1217-9

McConnell, T., Sturm, T., Stevenson, M., McCorry, N., Donnelly, M., Taylor, B.J. and Best P. (2019). 'Co-producing a shared understanding and definition of empowerment with people with dementia', *Research Involvement and Engagement*. *5*(19). https://doi.org/10.1186/s40900-019-0154-2

Mockford, C., Seers, K., Murray, M., Oyebode, J., Clarke, R., Staniszewska, S., Suleman, R., Boex, S., Diment, Y., Grant, R., Leach, J. and Sharma, U. (2017). 'The development of service user-led recommendations for health and social care services on leaving hospital with memory loss or dementia – the SHARED study', *Health Expectations*. *5*(19). https://doi: 10.1111/hex.12477.

Novek S. and Wilkinson, H. (2019). Safe and Inclusive Research Practices for Qualitative Research Involving People with Dementia: A Review of Key Issues and Strategies. *Dementia*, *18*(3), 1042–1059. https://doi.org/10.1177/1471301217701274

Phinney, A., Kelson, E., Baumbusch, J., O'Connor, D., and Purves, B. (2016). Walking in the neighbourhood: Performing social citizenship in dementia. *Dementia*, *15*(3), 381–394. https://doi.org/10.1177/1471301216638180

Reynolds, L., Innes, A., Poyner, C., and Hambidge, S. (2017). 'The stigma attached isn't true of real life': Challenging public perception of dementia through a participatory approach involving people with dementia (Innovative Practice). *Dementia, 16*(2), 219-225. doi: 10.1177/1471301216635828.

Shakespeare, T., Zeilig, H. and Mittler, P. (2019) 'Rights in Mind: Thinking Differently About Dementia and Disability', *Dementia*. *18*(3),1075-1088. https://doi: 10.1177/1471301217701506.

Stevenson, M., Savage, B. and Taylor, B.J. (2017) Perception and Communication of Risk in Decision Making by Persons with Dementia. *Dementia*. *8*(3),1108-1127. https://doi.org/10.1177/1471301217704119

Tong, A., Sainsbury, P. and Craig, J. (2007) Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, *19*(6), 349-357. https://doi.org/10.1093/intqhc/mzm042

van der Wardt, V., Bandelow, S. and Hogervorst, E. (2012). The relationship between cognitive abilities, wellbeing and use of new technologies in older people. *Gerontechnology*, *10*(4), 187–207. https://doi.org/http://dx.doi.org/10.4017/gt.2012.10.4.001.00

Wiersma, E. C., O'Connor, D., Loiselle, L., Hickman, K., Heibein, B. Hounam, B. and Mann, J. (2016). Creating space for citizenship: The impact of group structure on validating the voices of people with dementia. *Dementia*, *15*(3), 414–433.

https://doi.org/10.1177/1471301216642339

Williamson, T. (2012). *A Stronger Collective Voice for People with Dementia*. York. Retrieved from https://www.jrf.org.uk/report/stronger-collective-voice-people-dementia accessed 3 August 2021

World Medical Association (2018) *WMA Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects* Retrieved from https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/ accessed 3 August 2021

Table 1: Pre Interview guide questions

1. Can I first ask whether you are a person with dementia or a care partner of a person with dementia?
2. How long have you been living with dementia?
3. How old are you?
4. Has living with dementia impacted upon your social life?
5. Has living with dementia influenced your daily routine? If so how?
6. What is important to you for you to be happy? Has this changed since living with dementia?
7. Has your sense of wellbeing or happiness been influenced by living with dementia? If so how?
8. Have you encountered any feelings of loss or gain as a result of living with dementia?
9. What did you do to occupy your time prior to living with dementia? What do you do to occupy your time now?
10. What made you want to become a Dementia Associate?
11. What are your expecting from the Dementia Associate Initiative?
12. Do you think being a Dementia Associate will have a positive impact on your wellbeing?

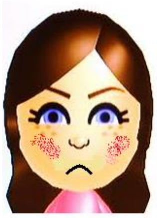
Table 2: Post interview and focus group guide questions

- What has being a dementia associate meant to you over the past 14 months?
- What has being a dementia associate been like?
- Has being a dementia associate impacted upon your social life? If so how?
- Have your initial expectations of the dementia associate role been fulfilled?
- How does being a dementia associate made you feel?
- Do you feel valued as a dementia associate by the University of Salford Dementia Institute (SID)?
- Has your sense of wellbeing or happiness been influenced by being a dementia associate? If so how?
- How much of a time commitment is being a dementia associate?
- How do you feel about this time commitment?
- How does being a dementia associate compare to the other community engagements you are involved with?
- What have you achieved as a dementia associate either individually or as a group?
- Do you feel your input has influenced the SID research and community engagement agenda? (Prompts- Education, Research topics, groups, public engagement)
- Is there anything you would like to discuss that has not been covered?

Table 3. Self-report questionnaires

1)Please indicate how you are feeling **after** today’s meeting

Very Happy Happy Neutral Unhappy Very
Unhappy



2)Did the meeting give you the opportunity to raise issues of interest to you?

Yes ☐ Somewhat ☐ No ☐

3)Did you raise issues at the last meeting that needed action?

Yes ☐ No ☐

4)If so, were these issues actioned or addressed further today?

5)Did today’s meeting help your involvement in the following SID activities?

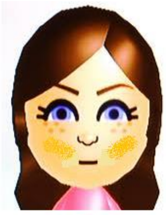
Research	Yes ☐	Not Applicable ☐	No ☐
Community Engagement	Yes ☐	Not Applicable ☐	No ☐
Awareness Raising	Yes ☐	Not Applicable ☐	No ☐
Education	Yes ☐	Not Applicable ☐	No ☐
Other (Please specify)	Yes ☐		No ☐

6)Did today’s meetings help your involvement in activities of interest to you?

Yes ☐ No ☐

7)On the scale below how much did you enjoy today’s meeting?

Very highly Highly Average Unenjoyable Very unenjoyable



8)Why did you enjoy or not enjoy today’s meeting?

9)How confident are you that your input today will lead to change and/or be actioned in the near future?

Very confident ☐
Confident ☐
Somewhat confident ☐
Doubtful ☐
Very doubtful ☐

10)What could have been done to improve today’s meeting?

11)Today’s meeting met your overall expectations

Agree ☐
Slightly Agree ☐
Neither Agree nor Disagree ☐
Slightly Disagree ☐
Disagree ☐

12)Any further comment not covered by the questions above