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‘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

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Title: *'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

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Abstract (168 words):

This paper presents the work of the 'Salford Dementia Associates Panel', based at the Salford Institute for Dementia, Salford University (UK). We discuss the roles of the Dementia Associates, in particular around the areas of engagement and research. The panel is made up of people living with dementia, and current and former care partners. It highlights the development of this group over a four year period and demonstrates over time how the role of a Dementia Associate member has evolved. The panel is involved in research, education and public engagement activities conducted by staff and students within the Institute. The motivations for becoming involved are clearly articulated and demonstrate how the personal backgrounds of individuals have driven the collective involvement and desire to bring about change. The benefits and challenges associated with working as part of a panel are discussed. We conclude by bringing together our experiences as a set of suggestions for others who may wish to create a similar forum to promote the involvement of people living with dementia and former and current care partners.

PAPER (3816 words)

INTRODUCTION

Involving people living with dementia, their care supporters and care partners has become an increasingly important area for research to take into account (Swarbrick et al 2016, Scottish Dementia Working Group 2014) with early work focusing on user advisory groups and panels (Corner 2002). Yet, initial examples of people living with dementia being involved in providing advice to researchers was relatively rare (McKillop and Wilkinson 2004). This paper contributes to the growing evidence base that it is possible to include people living with dementia in many ways in the research process (Bethel et al 2018). We have co-written this paper as a team of people living with dementia, current and former care partners and academics based on our work together developing the 'Salford Dementia Associates Panel'.

BACKGROUND

In late 2014, a small group of individuals with experience of dementia, either living with the condition or as a carepartner or supporter met with researchers from the University of Salford to explore the possibility of engaging in partnership work to make a difference to those affected by the condition. At that time, co-production in dementia research was gaining popularity (Scottish Dementia Working Group 2014),

though the reason for the coming together of our group was not to meet the requirements of research funding calls. Rather, the group wanted to raise awareness of dementia and contribute through a collective effort to improving the lives of those living with the condition. This was the beginning of what was to become the Salford Dementia Associates Panel at the Salford Institute for Dementia (Salford, UK).

Throughout 2015, the group met on a bi-monthly basis to share ideas and experiences. The early meetings were very much about getting to know others and social involvement, usually over coffee. The group bonded quickly and friendships formed. While the chats and friendship bonds were appreciated, the group was keen to do more to raise awareness of dementia and decided to host a 'Good Life Festival' to promote the idea that it was possible to live well with dementia. Although still informal, the meetings took on a purpose, with the group drawing plans for the event with the support and input of the University.

The success of the Festival (see Luxmore et al., 2018) galvanised the group to do more, for example around awareness raising, providing activities, and contributing to research and teaching activities. Although the term 'Dementia Associates' had been used by members of the group, it was felt that it would be useful to begin to separate out activities into two groups – one that met for the companionship afforded by the social aspects of what was to become SIDs [the Salford Institute for Dementia] café, still hosted at the university, and another, orientated around developing and taking forward plans for events and activities with the support of university staff. We also continued to get involved in initiatives to promote dementia awareness, including speaking to students at the university and publicity events held across Salford. Our ambitions were greater than this though. We knew that there was still a need for more activities and events for people living with dementia, not just in Salford, but across Greater Manchester. We also knew that if we wanted to grow the number of research and educational activities we got involved with we needed a dedicated space to do this.

The design and development of the 'Dementia Hub' to house our activities and act as a meeting place for our Dementia Associates Panel meeting became our second big project. The University had secured funding to build a dedicated Hub, designed around principles of good design for people living with dementia. We worked with the architect on the plans, providing input from our own lived experiences of dementia and caring for loved ones with the condition. Developing the Hub was an incredibly fulfilling activity, not least because we could see the impact our views were having on its design, but because we could see that our ambition to have a dedicated place in Salford was being realised. The Hub opened in May 2017 and has a meeting space, accessible toilets, a kitchen that we can all use, access to a lovely outdoor area and is on the ground floor to ensure people with any accessibility issue can easily enter the building. The lighting is bright, the seats are varied and comfortable.

By the time the Hub opened we had also introduced a range of other activities, including creative writing, art and craft work, and presentations from visitors on

various topics relating to dementia, and we still ran our café, though much of our time as Dementia Associates was spent planning the Hub.

By the end of 2016, our group of Dementia Associates had entered a transition phase. We were undertaking a range of activities for people affected by dementia, as well as being involved in awareness raising, education events, and advising on various research projects. We realised that some changes would be needed to enable us to continue to do all these things as well as make full use of the Hub. We also knew that we needed to think about how we could go about securing longer term funding for our activities.

We devised a set of 'terms of reference' (Box 1) that helped guide the work we did as Dementia Associates and the meetings became much more regular and, at our request, a little more formal, with minutes and action-points. The work we do now falls into four different groups:- A Good Life Club involving activities such as gardening and craft work; SIDS Café; a monthly Music Café that consist of a different concert delivered by professional musicians; and the Dementia Associates Panel.

The Dementia Associates are still a social group, but the emphasis of the meetings is a little more focused, and we get involved in advising on different aspects of research and engagement work across the University, as well as the sorts of activities we want to run as part of the other groups. In a way, we have become much more like a group of dementia activists raising awareness of dementia at public events sharing ideas with each other, and having input to research. While we know that it is not possible to take all the ideas forward, it is involving us in discussions about them that matters most. Our experience living with or caring for someone with dementia matters, and our involvement in the Dementia Associates Panel means that we can provide input and ideas, that will hopefully have a positive impact on the lives of others living with the condition.

BOX 1: Terms of reference for the Dementia Associates Panel

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 20 individuals – we would aim to have a minimum of 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 on:

1. 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 (for example newsletter, website, videos, interviews).
5. Fund raising for the activities run in the Hub
6. Reviewing institute outputs (e.g. newsletters, bids, community-based information leaflets).
7. Other activities as required in line with Institute activities

Benefits of Involvement

Our main motivation for being Dementia Associates is to influence change. We don't want other people to go through some of the things that we have had to go through (and are still going through), so it is important that we try and make services better for the people being diagnosed today and tomorrow. As people who have been affected by dementia we can use our experience and expertise to support dementia services across our city to achieve best practice and to operate in a way that is dementia friendly. Membership of the Associates Panel has given the opportunity for individuals to engage in research that has the potential to influence policy and practice and to talk to those people who can enable change.

“As Associates, research is one way that can influence change. We don't always tell them what they want to hear but what we are pushing the boundaries of research and information with our own experience” (Care Partner 1)

“...belonging to the Associates helps me to promote the work of the groups who are there to actively encourage participation in activities so that a person can continue to live a full and enjoyable life’ (Care Partner 3)

Being based in a university means that we are in the best place to help to educate the professionals of tomorrow. We have been involved in teaching nursing students about what it is like to live with dementia and encouraging them to see dementia through the eyes of those affected by the condition. The University Masters programme has benefitted from the involvement of Dementia Associates through, for example, recording several you tube podcasts available for students on University registered programmes.

We know that it is important for health care professionals to consider the reality of the person living with dementia and the care partner. This can only make them better practitioners. Some of the students we have spoken to have gone on to do their research projects about dementia. For example:

“I have worked in an advisory capacity for a post graduate student looking at the enabled environment and how the use of technology can assist...I also gave my opinion on how the use of technology would also assist carers, particularly when the carer themselves have health conditions or physical incapacity.” (Care Partner 2)

We have been engaged in disseminating research undertaken at the Salford Institute for Dementia to the general public, by speaking at Continuing Professional Development events, public lectures, panel events, research festivals and dementia conferences. We presented a paper to the Dementia Congress in 2016 and have also published an academic paper about a model for co-produced dementia events (Luxmoore et al., 2018).

As a group, we feel empowered because we are making a positive change. We also feel very privileged to be at the cutting edge of dementia research and to be the first to know about new discoveries being made in the academic world, be they about medicine, robotics, architecture or the arts. We were consulted by the architects and interior designers responsible for designing the Dementia Hub at the University to ensure that every part of it was ‘dementia friendly’ from our perspective. We have also been asked to review a number of research proposals to ensure that they effectively outlined the key messages of the proposed project in understandable ways. At present, we are helping to shape several research projects considering how to best support people living with dementia using creative arts. These projects are being developed with both academics at the University and external partners. As such, we are providing input into the early phases of research when ideas are being crystallised.

“Our expertise are being used in all parts of the University to help with research about dementia [,,] Part of being an associate is about people using and appreciating the expertise that we all have people living with dementia” (Person living with dementia 1)

The academics learn a lot from us but as well as contributing to emerging research, we are learning a lot too. We were recently given a tour of the University's biomedical laboratories and were introduced to new research into the causes of different types of dementia which is currently being carried out by some post graduate researchers.

"He gets an education for himself because he is listening to what people are saying" (Care partner 2)

It is exciting to be part of the team that helps to set the research agenda and to have a real influence over the research done at the University. We certainly feel a great sense of ownership over what is being done at the University and that is very powerful.

"With a diagnosis of dementia we can sometimes feel like we are losing control of things but being an Associate can change that because we are doing something positive and we are making the decisions about what is important for people with dementia in terms of new research". (Person living with dementia 1)

Associates have been involved as members of various Salford research project advisory groups where people with dementia were very vocal about their feelings and needs. Members valued the opportunity to hear how they truly felt as this promoted understanding between group members.

Being a Dementia Associate is a very social experience. All of the members of the panel are affected by dementia in some way and so know what others are going through. At times, living with dementia can feel very isolating and so it is important to be able to meet with people in a similar situation and who truly know how you are feeling. Through being Dementia Associates we have been able to meet new people and to make new and valued friendships. This can be so important when you are living with dementia as it can often be a lonely experience. We can offer each other advice, support or even just someone to talk to. We also feel a sense of belonging and inclusion within the group, everyone is included and everyone is important here.

"We still have a lot of value and we still have a lot to offer other people". (Person living with dementia 1)

Between us, we have so much knowledge and experience that can benefit society. All of these things have helped us to increase confidence in ourselves and as a group of experts. We know that what we are doing now will be beneficial to future generations and part of being an associate is leaving behind that positive legacy. We hope that what we do can be used for the better even when we have moved on.

"By being a Dementia Associate we can show people that we are still here and still living a full life. Our thoughts, our feelings and our knowledge still count. We are still valuable and still valued. By being an Associate we have been given a voice and we intend to be heard" (Person living with dementia 1)

REFLECTIONS AND SUGGESTIONS FOR OTHERS INTERESTED IN RUNNING A GROUP

Challenges

The Salford Dementia Associate Panel is a group we are all proud to be associated with. As a model for enabling people living with dementia and their care partners to have a voice and contribute to decision making it is a powerful approach.

However such groups do not come without their challenges! The first relates to the dynamics between individuals.

One of the important principles that we have embraced is the need to accept that other people's views might not be your views and that not everyone is the same.

"Sometimes one person and another have disagreed, and there has been a bit of altercation and it has been a bit uncomfortable." (Care partner 3)

"Need to realise that some people are a bit more sensitive than other people, and if someone does not like your ideas you should still be polite to them, because at the end of the day we are still human beings and we all need to be accepted for who we are." (Person living with dementia 1)

The facilitators of groups like ours need to have the ability to:

'manage strong minded people' (Care partner 4)

And the potential clashes of personality that can occur. Having terms of reference (as detailed in Box 1) so that people will know their role and agreeing at the outset respectful communication can help individuals know when they have gone 'too far' is important as these provide the mechanisms to collectively manage individual expectations.

Potential conflicts need to be recognised and dissolved quickly – needs clear leadership; a leader needs to be able to deal with this. (Care partner 2)

"have to accept that when you do empower people there will be consequences at times" (Care partner 5)

Facilitators of groups at the Institute vary from the Principle Investigator on a funded project, to students doing a research study, to our appointed community engagement workers. This means there is varying levels of experience working with people living with dementia. However the facilitator is, they need to be able to take into account different views and opinions in a fair minded way. The importance of all group members ability to remember that it is:

"Important to compromise" (Person living with dementia 2)

cannot be underestimated.

Why Get Involved?

Recruiting members of a group like the Dementia Associate Panel requires insight into the reasons why people might want to get involved. In our case our panel members have become activists in the sense that they wish to influence change.

“When we were given a voice at the start (e.g. prime ministers challenge), and now we have a voice, we thought influencers thought we would go away. Our voice started off as a whisper and now it is a great big roar” (Person living with dementia 1)

Some of our members have always been activists through their professional or community roles. Others had not considered themselves in that light but had always wanted to make a difference:

“I have always stood up for the underdog, but I would never have stood up in public and spoken to a group of people. Never, ever.... But since I have met with people and found I have a voice I think to myself well I might as well use it.....Coming to the hub [the venue for our meetings] lets me speak and that is why I come” (Person living with dementia 1)

Being able to have the confidence, and be able to maintain my confidence, to be able to continue to address people. If I wasn't involved in the DAP I would have lost my confidence and the skill I have to continue to stand up and speak to people” (Care partner 2)

“I found my voice when [husband] got dementia and there was no-one else to speak up for him” (Care partner 4)

Members speak of their involvement with the Dementia Associate Panel as helping with personal confidence and to ensure that their voices were heard and the needs of people living with dementia were recognised.

Lessons Learnt and Recommendations for Others

There are various groups who might want to set up a group like the Dementia Associates Panel such as other universities, care homes, NHS Trusts, Local authorities, and other organisations who wish to ensure that the views of people living with dementia and their care partners are heard.

In our view the key things to consider are:

- the venue for meetings. We are very fortunate at Salford Institute for Dementia to have a purpose built space, the Dementia Hub, that we were involved in designing.
- The principle of inclusivity is vital. As we have developed, we have consciously welcomed new visitors to the Dementia Hub and invited people to become members of different groups at both the University and in the community and also to join the Dementia Associate Panel. Not everyone wants to be on the panel; they prefer to attend other groups we run for social contact, fun and learning opportunities.
- Ensuring that people living with dementia and care partners are valued and opportunities available to all on the basis of age, gender, disability is key. In the words of one of our members: *Do not “segregate”* (Care partner 2)

In summary, there is the need for some guiding principles: those that are most important to our group members are; inclusivity; a welcoming social environment; an accessible physical environment; and that the group meets their needs.

As can be seen, over time our Dementia Associate Panel has evolved from a social interaction with some 'business' items to a fully functioning Panel where our members have developed the Terms of Reference with the support of Institute staff, have decided on when they wish to have the minutes circulated and in what format, increasingly contribute to the agenda of the meetings and have very clearly worked out what it is that they personally and collectively wish to achieve.

Our 'top tips' for establishing a similar group are therefore:

1. Ensure members know what is expected of them (our terms of reference helped us).
2. The group needs to have purpose and meaning – not just a group for people to turn up to for a chat. The group needs to be able to use the information and the experience that the people who attend in practice.
3. Need to listen to the ideas of people who attend the group and act where possible– not a tick-box exercise
4. Needs to be a smaller group to be able to accomplish things. Too many people means that meetings are difficult, there are too many competing ideas, and it is difficult to get things done. Our biggest attendance has been 24 members at any one time.
5. Need to have a mechanism to enable more new people to join. We acknowledge the need to include people with fresh ideas
6. This can raise issues of how to integrate new people with long-standing but our group has successfully navigated this due to underlying ethos of inclusivity and valuing everyone.
7. The motivation of group members needs to be acknowledged for our members – Our members have said the main reason for their involvement is a recognition that *"this could be me"* (Care Partner 4) *"I am trying to future-proof future dementia services and what is out there"* (Care partner 2)

The work we have done has stemmed from a foundation based on a perceived need, and has grown due to the sense of accomplishment that being part of an active group with a clear remit to inform and influence.

"It is nice to see something that you have said, and someone seeing the value of that, and seeing the outcome of it. That is very satisfying." (Care Partner 4)

From a University perspective, the work we do is greatly enhanced by having the involvement of people living with dementia and current and former care partner. It helps to ensure the work we do has real world relevance. Something that is important to everyone who is involved in the Salford Dementia Associates Panel.

CONCLUSION

We believe our Panels' success is due to the mutual benefits for all involved and that we can see change and improvement occurring as a result of the work we do. We are inclusive and respectful of different members contributions and we have fun! Our activities go beyond research advising and even the doing of research. The importance of relationship between the group and the academics to enable ideas to be shared, developed cannot be understated. Importantly, the benefits of the panel reach beyond doing the research to include sociability and belonging, having purpose, and widening public understandings of dementia based on an (academic AND an experiential) evidence base.

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