

Reflections on PPI from the ‘Action on Living Well: Asking You’ (ALWAYS) advisory network of people with dementia and carers as part of the IDEAL study

Members of the ALWAYSs group*

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Abstract:

This article describes the work of the ALWAYSs group - an involvement group of people with dementia and carers attached to the IDEAL research study. The article describes the work of the group, the methods that have helped them to stay involved and people's perspectives on their experiences of being involved and the impact it has had, for themselves and others. The article has been written following a reflective piece of work with the ALWAYSs group to review and remember the work of the past four years. An accompanying film brings to life the work and activities of the group, available at www.idealproject.org.uk

Introduction:

The ALWAYSs ("Action on Living Well: asking you") group is an involvement group of people with dementia and carers. The group has a rolling membership and consists of 4 people with dementia (3 who regularly attend organised meetings) and 5 carers or former carers who contribute regularly. Other people with dementia and carers have been involved in occasional meetings to discuss additional study materials. People with dementia are supported to be involved by the organisation Innovations in Dementia, whilst carers are supported by the research team at the Alzheimer's Society. The ALWAYSs group was formed in 2014 at the start of the IDEAL research project. The group's role is to advise on different aspects of the project as needed by the project team, based on personal experiences, skills and expertise.

The participants in the IDEAL study are people with dementia and carers who are followed up over a number of years, to see how people's lives change. IDEAL will result in action plans about what can be done to enable people to live well with dementia to assist policy makers, purchasers and providers. There will also be guidance and advice for people with dementia and their families about steps they could take to enhance their lives. More information about the IDEAL study can be found at www.idealproject.org.uk

This aim of this article is to describe the involvement of the ALWAYSs group in the IDEAL study. Much of this article is derived from a recent focus group discussion between 8

members of the ALWAYSs group and the project team, facilitated by Rachael Litherland from Innovations in Dementia. This method was a great way of reviewing and remembering the last few years of work:

“Right okay, well I’m feeling enthusiastic and reignited really, I’m curious to see the results and [feeling] a bit militant” (carer).

Consequently, most of this article is written from the perspective of ALWAYSs group members.

The aim of Patient and Public Involvement (PPI) in the IDEAL study

The project team have been very clear about the enormous benefits and the very significant contribution that the ALWAYSs group has made to the development, implementation, analysis, interpretation and dissemination of the IDEAL project. This includes shaping project materials, providing feedback on questionnaires and interview processes, reviewing emerging theoretical themes, and presenting project findings alongside the research team. Few studies that involve users examine the impact of participation in research on user group members (Beighton et al, 2017). We therefore took part in an evaluation event to explore, in detail, the experiences of being involved in the project and the impact it has had upon us. This was conducted in February 2018 in London by a combination of a focus group and the creation of a short film, with 7 members of the ALWAYSs group.

In the focus group, we talked about people’s motivations for joining ALWAYSs, the ways that people had been involved, how they felt about their involvement, the relationships they had with the researchers, whether people felt they had made a difference to the research and the lessons that they would like to share with other researchers. The principles outlined in Staniszewska et al. (2017) about improving PPI in research were used to inform the focus group discussion and to make sure that we could talk about our experiences.

On the same day, we worked with a graphic artist and film-maker to create a short film, building on the issues discussed in the focus group. The film describes the ALWAYSs

group, how they work and what they do (available on the IDEAL study website: www.idealproject.org.uk) Most importantly, the focus group and making of a film gave us all – people with dementia, carers and researchers - a chance to think about the benefits of being involved in the ALWAYSs group.

Methods used to incorporate PPI in the study

The researchers wanted our involvement to run as a thread throughout the IDEAL research study, and had built some proposed methods into their original research application. Staff from Innovations in Dementia and Alzheimer's Society helped to identify potential members of the group, helped people to understand the purpose of the group and provided practical support from the outset to set up the ALWAYSs group, discussing with us how this group and our involvement might work in practice. The intent was that people should be able to be involved (and stay involved) using the method that best suited them. For most people, this has been by attending ALWAYSs meetings, which have been held at critical points of the research. But others have given their input via one-to-one meetings, telephone discussions and emails. Some members of ALWAYSs have presented about their role at conferences and events, and attended the study's larger project advisory group meetings and additional study meetings. Pre-identified principles of supportive involvement for people with dementia were adopted in meetings (Litherland and Capstick, 2014) including building trust, meeting regularly (and keeping contact between meetings), providing supportive environments, having sufficient time and being flexible, adapting written materials and providing cues and prompts.

Our focus group also served as an important method of thinking about the impact and outcomes of our involvement - beyond the immediate benefit to the research study. These are the things that have helped us to be involved.

(1) We created a group identity:

The group was named at our first meeting in Autumn 2014. A name helped to distinguish this group and its role in relation to the IDEAL research project, it helped to build our identity as a group and reminded us of our role.

“...because we had the IDEAL...there was a danger of it kind of slightly getting lost I suppose, without a marker to identify it” (carer)

(2) Meetings are accessible:

We have commented on a lot of research documents. The IDEAL researchers have also come to meetings to talk about their plans and ideas. They present them in an uncomplicated way, and often use diagrams and pictures to help us to understand and remember. We usually have a lot of questions. The research team answered these, and explain why some things have to be done in certain ways in the research. Recently we gave feedback on their proposed conceptual model that explains the factors that contribute to living well with dementia. It could all be really complicated, but it is made easy to understand, documents are produced in large print and are not too long.

“[there’s] a lot of support to us to get here for a start and to have good paperwork which we can understand. You know, you don’t overwhelm us with stuff, the stuff that we receive is relevant, we can understand it” (person with dementia).

Meetings are not rushed, and usually begin with an informal lunch where everyone can relax and catch up with each other. Meetings are usually held at the same location - a pleasant building in London, within easy access of public transport. The rooms are on the ground floor, and the team put up signs to help us find our way back from the toilet! Travel is organised and booked for people who need this, with some people arriving in taxis, door-to-door.

“Anybody who’s wanting to have people coming to a meeting somewhere has to be careful about the location, and the facilities and very clear directions because the anxieties about getting somewhere. Those can put you off and make you feel unnerved when you get, before you get there” (person with dementia).

(3) By working together regularly, we created a team:

The group membership has been fairly stable over the lifespan of the research, with extra people joining occasionally, e.g for a photography meeting to discuss a connected project, 'A Life More Ordinary'. We formed a team. This gave us confidence to speak out, but also a safety net of support to find our voices. We respect and trust each other.

“[It] goes to the top of the pyramid, and it’s, that, we bounce off each other with ideas and thoughts and...(carer)

It’s an affirmation of our own values isn’t it? (carer)

Yeah, and you do really feel part of something quite strong and important” (person with dementia).

It has also been important to meet regularly - 2 or 3 times a year, with contact in between meetings via email and phone calls. In this way we have remained attached to the project.

(4) We feel that our contributions have been valued by the research team

We have done a lot of work. We are paid for our role following INVOLVE (www.invo.org.uk) user involvement rates - this recognises and values our contributions. The research team have been very positive about our work, and they tell us what has changed because of our involvement. It is important to know that our contributions are making a difference and it is worth our efforts.

“I think it’s all been helpful. I remember one of the initial suggestions was about having open-ended questions in the questionnaire, and it was your suggestion and there’s some great data come through because they went into the questionnaire, and that was an early suggestion from the group. We put it in...” (researcher).

(5) We’ve formed positive relationships with the research team - they make us feel part of their team

Although the ALWAYSs group has a separate identity, we do feel connected to the IDEAL study. The rapport and relationships we have built with the research team are very important:

“That’s where it comes down to relationships as well, sometimes these researchers are just like an anonymous person. On this project they’re not.” (carer)

We've delivered presentations about IDEAL and ALWAYSs alongside the research team. We know that they talk about us in their presentations and are proud of the existence of ALWAYSs. We feel part of this important research and like partners, not just add-ons.

Results of PPI in the study

In discussing our involvement in IDEAL we were reminded of some of the ways we have contributed to date (see Table 1).

Table 1. contributions of the ALWAYSs group to the IDEAL study

During 2018
Participated in a focus group discussion to reflect on the ALWAYSs group
Made a short film about the ALWAYSs group (for release in May 2018)
During 2017
Reviewed study progress
Reviewed some of the findings from IDEAL T1 data.
Consulted about the continuation of IDEAL with the funding application for IDEAL-2 (which has now been funded).
Represented IDEAL at the British Gerontology Society Conference in Swansea, July 2017.
Contributed to an ESRC Festival of Social Science event in Exeter November 2017.
During 2016
Reviewed study progress.
Members took part in piloting of the qualitative interview for IDEAL – this is now published
Consulted about the research process and contributed to training.
Discussed a new measure to look at how people with dementia think about their condition.
Represented IDEAL at UK Dementia Congress 2016 in Brighton.
During 2015
Consulted on the questions we ask in the study questionnaires.

Advised the project on the introduction of data linkage to IDEAL.
Met with the photographer to discuss the linked project 'A Life More Ordinary'
Helped by being involved in piloting of the IDEAL interviews
During 2014
Inaugural meeting of the ALWAYSs group
Provided feedback that was used in the training of researchers who work on the study.

As we discussed how we were involved we also noted some benefits for us as group members.

During the focus group we realised we were all involved because we felt connected to the research subject of living well with dementia. This was recognised as our expertise by the research team, but also made the whole experience much more meaningful for us:

“I think you begin by starting to try and develop your own strategies because it’s in your face. You know, you can’t avoid it, you’re living with it, you learn your own strategies, so, erm, at that point when you come and meet other people it’s brilliant because you then start refining those in relation to the wider variety of experience.” (person with dementia)

Being involved has been restorative; it’s given people a role, a job, and a community of interest:

“What this project has done is helped give me confidence and when you’re diagnosed with dementia one thing it robs you of is confidence because you give up your job, you give up often friends because they desert you... it robs you of a lot of things and what projects like this do is it begins to restore your person-hood, you as a human being.” (person with dementia)

A positive outcome from being involved in ALWAYSs has been the way that quieter voices can find their space:

“Well I get a lot of, bits and pieces here and there... and you’ll see me just sitting here and when it comes out, I’ll start babbling on about something in the group. It’s only in the group, it would be no one else.” (person with dementia)

And this can be of a real bonus for family members who have gotten used to the quietness:

“It surprises me sometimes what he comes out with. It shocked me. It really shocked me, yeah” (carer).

It’s also been positive that we’ve been taken seriously by the researchers:

“I would say that they’ve been very positive in the sense of having a chance to knock ideas off against the academics because that’s where, at the end of the day the stuff, the figures that you’ve got from the actual working with these people, they are real aren’t they?” (carer)

“They’ve come to sit at the feet of the masters and mistresses haven’t they?!” (carer)

During our focus group, there was a lot of discussion about the time-lag when waiting for results in longitudinal research. As an involvement group this sometimes meant there were ‘quiet’ periods which not much work to do:

“That involvement can get a bit lost in the middle and that’s something that people could guard against” (carer).

Additionally, it can be frustrating waiting for results to be gathered and disseminated, especially when you feel so connected to the research subject. We realised that the speed at which we want to see the results of research shared with the wider public can be at odds with the work the research team has to do. The experience of living with dementia brings an urgency to wanting to see positive changes in policy and practice, which this research brings:

“the clock is ticking and I want things to be happening quicker than perhaps they can happen.” (person with dementia)

Discussion

The ALWAYSs group has been an integral part of how IDEAL has been delivered, with members contributing routinely and at key study points which have benefitted from the critical (but friendly!) eye of people with dementia and carers. The research team have brought their ideas, questions, materials and concerns to the ALWAYSs group at regular intervals - ensuring that the role of the group has been routinely linked to the timetable and action plans for the research. Researchers have always responded in a timely, understandable and supportive way to queries and comments from the ALWAYSs group, acknowledging the importance of their role, and valuing this with financial recompense.

Without the involvement of people with dementia and carers, we do not think that the study processes, materials and emerging outcomes would be as clear and relevant.

An important reflection for us has been how much we have got from being part of the ALWAYSs group. A job, a role, to be listened to, to effect change, to be involved in creating something better than if we hadn't been involved, to be valued. This is what 'patient and public involvement' is all about.

Lessons for practice

- PPI should run throughout your whole project
- It takes time and effort. Be adaptive, flexible and find ways to work differently. Build the confidence of researchers.
- Make sure you cost PPI into your research bid. This includes accessible venues, lunch and refreshments, transport (and other expenses) and payments
- Build trust, communication and rapport between people who are involved and the research team. Small and informal helps here.
- Work on the principle of creating a partnership between people with dementia and carers and the research team - rather than PPI being an add-on.
- Have regular contact with your PPI group - meet face to face more than once a year, and keep in touch by email, updates, and telephone calls
- Listen and give people feedback and say what has changed because of their input. Provide regular updates including study progress.

Reflections on PPI by researchers and the ALWAYSs group

It's not easy to start off on this involvement journey. It can be hard to convey what is expected of people in the early days and how this collaborative relationship will work:

“Going back to that very first meeting...I thought I'm not sure this is going to work, but actually that negative is a positive because they were starting with not exactly a blank

canvas, but they were starting with wanting to listen to the voice of carers, the voice of people with dementia in order to make the thing work.” (person with dementia).

In terms of the structure of the group, we agree that it is helpful to have the support of an external facilitator. The facilitator acts as a broker between the research team and the ALWAYSs group and can concentrate on what the group needs to be properly involved. By having a member of the research team at the meetings this means they can respond to questions and concerns as they emerge.

On reflection, in the early days of setting up the ALWAYSs group it would have been helpful for the research team to have met with the group more informally before starting on the work. A rapport has developed over time, but this could have been nurtured at the beginning before the rush and pressure of project timelines took over.

There is a strong message from the ALWAYSs group that PPI should not be done for its own sake or for tokenistic reasons. The group recognises that researchers can sometimes be unconfident and worried about upsetting people with dementia and carers. Creating a bridge between people with dementia and carers and the research team and taking your time to build a respectful relationship will result in benefits for you and your research study, but also for the people you seek to involve.

Conclusion

Embrace PPI! Research benefits from our involvement - we put a lot in, and can get a lot out as well if the process is organised well. Go with the group - make the most of them, engage, have fun, provide cake, and mostly, be proud of them:

“We might have slightly different ideas but usually you see a lot of nodding heads,we, one person will say something and then other people will chip in and it grows, and really becomes quite strong” (carer).

References

Beighton, C., Victor, C., Carey, I., Hosking, F., DeWilde, S., Cook, D.,...Harris, T. (2017) "I'm sure we made it a better study...": Experiences of adults with intellectual disabilities and parent carers of patient and public involvement in a health research study. *Journal of Intellectual Disabilities*, ISSN (print) 1744-6295 (Epub Ahead of Print)

Litherland, R & Capstick, A (2014) Involving older people with dementia in service development and evaluation. *pp397-413* In *Excellence in Dementia Care – research into practice* (eds) Downs, M and Bowers, B. (McGraw Hill)

Staniszewska, S., Brett, J., Simera, I., Seers, K., Mockford, C., Goodlad, S., . . . Tysall, C. (2017). GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *BMJ*, 358. <http://www.bmj.com/content/358/bmj.j3453.abstract>

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