

Our reflections of Patient and Public Involvement in research as members of the European Working Group of People with Dementia

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Introduction

Alzheimer Europe has always been keen to promote the involvement of people with dementia in its work and consequently set up the European Working Group of People with Dementia in 2012. Over the years, the European Working Group of People with Dementia has been increasingly involved in research and in European projects. Alzheimer Europe realised the need for a proper structure and ethical approach. There is not a great deal of literature specifically about Public and Patient Involvement of people with dementia. Alzheimer Europe therefore engaged in Patient and Public Involvement activities with the European Working Group of People with Dementia with little guidance about the best way to do this. In 2017, following discussions with INTERDEM,¹ it was agreed that Alzheimer Europe (in collaboration with INTERDEM) should perhaps develop its own position which could then be used and adapted by other researchers. It was considered very important to involve people with dementia and their carers from the very start. The members of the European Working Group of People with Dementia and their carers were ideally placed

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and keen to draw on their personal experience and share their views about how to conduct Patient and Public Involvement in a way that is mutually beneficial for people with dementia, carers and researchers.

At that time, the European Working Group of People with Dementia comprised of 10 men and women with different types and stages of dementia from different countries (see <https://www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/European-Working-Group-of-People-with-Dementia>). The members had already acquired some experience of Patient and Public Involvement in several European studies, and some at national or regional level. They were therefore experts by experience who could add a unique perspective on the topic. They were actively involved in drafting and commenting on the position paper.

The position paper was written in the course of 2017 and was approved by the Boards of Alzheimer's Europe and INTERDEM (Gove et al., 2018). The Chair of the European Working Group of People with Dementia is a full member of the Board of Alzheimer's Europe and therefore in that capacity also approved the position paper on behalf of the European Working Group of People with Dementia.

The position paper discusses the concept of Patient and Public Involvement and highlights seven key areas which form a framework for the development, implementation and monitoring of Patient and Public Involvement work in the context of dementia research. These areas are as follows:

1. Determining, planning and involving people with dementia in the research process
2. Establishing and respecting roles and responsibilities
3. Promoting and protecting the rights and well-being of people with dementia
4. Training and support
5. Managing information and input resulting from Patient and Public Involvement
6. Recognition and acknowledgement of the contribution made by people with dementia
7. Promoting an inclusive approach to research and creating the necessary infrastructure for Patient and Public Involvement in dementia research

In the position paper, we encouraged researchers in all domains (for example, psychosocial, biomedical, clinical trials and care-related) to seize the opportunity and to further reflect on and improve the way that Patient and Public Involvement is conducted in the field of dementia. We are therefore taking this opportunity to reflect on some of these elements and our continued personal experience of putting these ideas into practice. Three of the seven key areas are addressed as these corresponded to the interests of the experts by experience, and, as we believe, they tend to receive less attention.

Section I – Recognition and acknowledgement of the contribution made by people with dementia

In everyday life, people are generally acknowledged for things they accomplish. However, when people contribute to research in the context of Patient and Public Involvement, they are invited to donate their time, to carry out tasks and to share their knowledge and experience not only freely but often without any further feedback or sign of gratitude. Researchers typically put a lot of effort into preparing materials and taking measures to ensure the wellbeing and meaningful contribution of people with lived experience of

dementia but do not give the same level of attention to providing appropriate feedback and to thinking of ways to acknowledge their contribution. This can include a token gesture or some form of payment. Another relevant area refers to publications and how to acknowledge their contribution to the research.

Chris Roberts, Vice Chair of the European Working Group of People with Dementia

My personal experience and perspective on the recognition and acknowledgement of the contributions made by people with dementia, as an expert by experience in my own right, is that I should be considered as a person with knowledge of my illness in a context that a researcher might not have experienced or understand, so I should be treated as an integral part of the project, not just a number or a tick box for involvement and extra funding.

I am or should be a part of the research team, a co-researcher and as such receive any prior training and knowledge that any member of the team will need to contribute effectively and efficiently. I should not just be seen as a person with a diagnosis of dementia, but as still a person who had or has a past, a previous life, maybe with huge relevance to your research. I might, for example, be or have previously been a researcher, a professor or a consultant. There is always a person behind every illness, condition or disability.

We should be named and recognised as a team member/researcher/contributor in any literature produced and on any papers or other findings. To be acknowledged in this way is very much appreciated and helps build good relationships with the scientific and medical community, which then sets standards for others and reminds them of the value of Public and Patient Involvement.

We are usually treated, informed and supported very well, with consideration given to our needs, preferences and disabilities, but the researcher/university/organisations do not always give the same level of attention to providing appropriate, regular feedback and to ways to acknowledge our contributions and the hard work which can be both physical and mental.

This can include a token gesture, flowers, chocolate, a small gift or card, maybe some form of payment or voucher. Something that shows some personal effort and consideration.

Something that is usually never considered is the sense of purpose, value and confidence that can be a knock-on effect for the experts by experience. This can make such a difference to living with a life-changing illness and encourages others to take part and promote further engagement. A 'thank you' means so much more when not just given verbally, but also acknowledged in publications of our contribution to the research.

When also reinforced in print, one can see a statement that can refer to a memory when these memories can be easily lost. It can be a great legacy and loving memory for the relatives of the research work done, for them to keep and treasure forever.

Section 2 – Promoting and protecting the rights and well-being of people with dementia

Even though people with dementia contributing to Patient and Public Involvement in the context of research are not research participants, ensuring their wellbeing is of paramount importance. A key issue is to ensure that the people involved understand what is expected of them, what is involved and that they have enough information so as to feel comfortable contributing and able to do so in a meaningful way. Even in the context of Patient and

Public Involvement, topics can still be sensitive (for example, in relation to palliative care or the progression of dementia). In some cases, there may be unforeseen reactions based on people's personal experience. This has to be carefully considered when organising Patient and Public Involvement activities. In addition to wellbeing, rights (for example, in relation to autonomy, respect for dignity and personhood, to have your own opinion, to be properly supported) must also be respected.

Helen Rochford-Brennan, Chair of the EWGPWD

My perspective on Patient and Public Involvement has evolved as I have evolved as an advocate. When I first spoke about living with dementia and was asked to participate in research, I was delighted, grateful and eager to have my voice heard. But now I have come to view Patient and Public Involvement as fundamental to any research project, not an add-on and certainly not something for which I should be grateful.

People living with dementia can be denied their human rights from the time of diagnosis. We are not always respected or informed. As we live with the disease, we navigate systems and structures which are not person-centred or rights based. As a result, either deliberately or by omission, our human rights are denied.

A rights-based approach to research can begin to address this inequality. Quality patient engagement should underpin all research projects, and such engagement must be from a human rights perspective. This engagement is only worthwhile if the person is empowered, and if there is a shared power and decision making.

I believe best practice is to involve people living with dementia from the start. I do not simply want to answer questions, I want to set the question, think about the issue that merits questioning. We must move from being research participants to being research instigators. And, critically, we have a right to be involved in the governance and management of a research project.

I am not an expert in law or medicine or human rights. But I am an expert in my own experience. People living with dementia must be valued like other experts. This means we should be remunerated for our time and not have lengthy waits for reimbursement of expenses. When I speak at conferences or attend a research event, I may be the only person in the room not being paid to be there.

Prompt payment of expenses and if possible ensuring the person with dementia does not have to pay for travel and costs upfront has two critical effects; first, it places a value on the lived experience. Second, it allows for diverse people living with dementia to become involved in research. Financial barriers can be prohibitive for some experts by experience.

I am heartened by the amount of invitations which I receive. I am a proud member of many research committees, steering groups, boards and panels.

But not everyone who issues an invitation has a clear understanding of how to support me appropriately. People living with dementia need support to disseminate reports and research documents. We need time and space to work and should not be put under pressure. We need a designated person to be our regular contact. We need opportunities to ask questions and discuss material informally before a formal meeting.

We also need practical supports with travel, expenses and planning. I want to be very clear, however, that we do not need a paternalistic approach, rather one that is inclusive and transparent. Requiring support does not make me less of a person or participant.

People whose dementia has progressed should be communicated with by skilled research professionals who understand their unique and individual communication needs. Particular effort should be made to ensure that their voice is heard and that the research community is not oversampling those living with young onset dementia.

Due consideration must be given to the aftermath of research. If I take part in research, I want to know the outcomes. Too often, people living with dementia are asked for their opinion or to share the lived experience and have no idea where it goes. What happened next? Did the work influence public policy or care practice? Is there a next step and does that next step continue to involve people living with dementia?

Being involved in research is empowering. From a personal perspective, it gives me a sense of hope. It's been a great pleasure for me to participate in many Patient and Public Involvement projects through Alzheimer Europe who have given me enormous support to make my involvement very easy. I am also very lucky to be involved with numerous Patient and Public Involvement projects in Ireland where I also get great support through the Alzheimer Society of Ireland, its important I acknowledge their support and that of my volunteer travel companion Carmel Geoghegan. It is my hope that the European Research community places Patient and Public Involvement at the heart of its dementia research and that robust patient engagement becomes the norm.

Section 3 – Training and support

Participating in research can be a bit daunting for some people with dementia. They might not feel that they have sufficient knowledge about research and/or the topic addressed. In medical research, technical language, jargon and abbreviations are often used. Participants should therefore be offered necessary support/training to enable them to take part. If people are involved over a prolonged period of time, this may need to be offered at different times. However, some people may have a research or health-related background and not need this. We should not forget that researchers themselves may need training in how to conduct Patient and Public Involvement with people with dementia and carers and in how to provide support.

Jayne Goodrick, wife/supporter of Chris Roberts

Chris and I have been involved in many pieces of research as participants, but being involved in the Patient and Public Involvement aspect of research has given us a confidence and a surety that we are no longer seen as 'just' patient and carer, but as full and equal members of a team, a team that is thrashing out all the issues and areas that a piece of work needs to have sorted before it can have any chance of going forward.

Mistakes have been made and corrected by all of us. This has been a learning curve. The involvement of experts by experience lends credibility to the piece of work, emphasising that due care has been taken in the formulation process. Of course, this must not be just a ticking-the-box exercise or mere lip service.

When first involved in Patient and Public Involvement, it was a little awkward for all involved, as is anything the first time you try, but with the genuine will of the professionals for Patient and Public Involvement, and their openness to listen to the experience of non-professionals around the table, an avenue for all to learn from each other was opened up.

Once reasonable adjustments were made (such as breaking down the literature into manageable sections; offering different methods of engagement, i.e. the choice between printed

or electronic versions of the papers, or whatever the person prefers; ensuring that easy-read versions are just that, easier to read and understand, not dumbed down, losing their essence and nuances), then these adjustments work for all, not just the persons with dementia!

Once the researchers saw the value and richness of Patient and Public Involvement, we became respected in our own right as team members, with opinions, knowledge and articulate arguments for or against a proposed action/plan/idea that comes from being experts by experience.

Some of this involvement starts off within a context of confusion, fear (on both sides) and insecurity of ‘Am I/are we capable?’ – again from both sides. But with organisations such as Alzheimer Europe, and our own UK-based Alzheimer’s Society, the will to take this forward, to ask us, the people living with and affected by dementia, what we want this participation to look like, has paved the way and produced a model for successful participation for ALL involved.

The greatest aspect of our involvement has been this change from being ‘patient and carer’ to being valued and respected members of the research team.

This has to be a win-win for all.

Conclusion

Involving people with dementia and their supporters in dementia research is a win-win for everyone involved. A lot of progress has been done in this area, although this may not be as wide spread as we would have hoped. If we want this kind of involvement to be more common and meaningful, certain areas need to be further explored in collaboration with people with dementia and supporters.

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Note

1. INTERDEM is a pan-European network of researchers collaborating in research on and dissemination of Early, Timely and Quality Psychosocial Interventions in Dementia aimed at improving the quality of life of people with dementia and their supporters across Europe.

Reference

Gove, D., Diaz-Ponce, A., Georges, J., Moniz-Cook, E., Mountain, G., Chattat, R., Øksnebjerg, L., & The European Working Group of People with Dementia (2018). Alzheimer Europe's position on involving people with dementia in research through Patient and Public Involvement. *Aging & Mental Health* 22, 723–729. DOI: 10.1080/13607863.2017.1317334

I am **Chris Roberts**. I am 58 years old, I have been living with mixed dementia (vascular and Alzheimer's) for about six years and have co-morbidities of emphysema and arthritis. I have been personally involved in lots of research projects, advisory groups and Patient and Public Involvement in the UK and Europe. I am a supporter of rights for people with dementia, including disability rights and issues, which I spoke about at the European Parliament in Brussels. I present and speak about all dementia-related issues, services and awareness in the UK, Europe and globally, having spoken as far away as Australia and Japan. I am Vice Chair of European Working Group of People with Dementia, Co-founder and Member of the 3 Nations Dementia Working Group. I have an honorary MSc in Dementia Studies and I am an Honorary Lecturer for Bangor University, North Wales.

My name is **Helen Rochford-Brennan**. I am the current Chairperson of the European Working Group of People with Dementia, and as Chair, I also sit on the Board of Alzheimer Europe. I am former Chair of the Irish Dementia Working Group. I have early-onset Alzheimer disease. Being involved in research gives me a sense of purpose and a great sense of achievement. My advocacy work gives feeling of empowerment and hope, and this would not have happened without my first research engagement which led me to the Irish Dementia Working Group. I have contributed to two books on human rights and legal capacity and I am currently writing a chapter for a book with a focus on rural dementia. In October 2018, I was awarded an honorary doctorate by NUI Galway for my work to uphold the human rights of people living with dementia.

My name is **Jayne Goodrick**. I am a former ambulance driver and former consultant in Chinese metaphysics. I run a family property rental business and portfolio. I have been a carer for my husband who has dementia and other various co-morbidities for the last 11 years. Using my experiences, professionally and personally, I have taken part in and supported my husband in many research projects and various Patient and Public Involvement work, giving advice and guidance to promote better understanding, care and services. I sit on various steering groups and hold various positions (Chair of Carers Advisory Panel for Dementia Carers Count, Dementia Engagement and Empowerment Project group facilitator and Expert Working Group for the Wales Dementia Action Plan, to name just a few). I was recently presented with the Prime Minister's 'Points of Light Award' for my voluntary work for dementia.

My name is **Dianne Gove**. My background is in psychology and psychotherapy. I have been working for Alzheimer Europe since 1996 and I am particularly interested in ethical issues and Patient and Public Involvement. In 2012, I obtained my PhD from the University of Bradford on the topic of stigma and perceptions of dementia. I am the Director for Projects at Alzheimer Europe and I am responsible for supporting the European Working Group of People with Dementia and Patient and Public Involvement work in collaboration with Ana.

My name is **Ana Diaz-Ponce**. I am a social worker by profession. I have worked for more than 20 years in the field of dementia and I have an interest in qualitative research and Patient and Public Involvement. In 2014, I completed my PhD in Trinity College Dublin on the topic of quality of life and anti-dementia drugs. Since then, I have worked at Alzheimer Europe as Project Officer, and as part of my work, I support the coordination of the European Working Group of People with Dementia and the Patient and Public Involvement work of the organisation.

My name is **Jean Georges**. Before joining Alzheimer Europe, I worked as a journalist and as a parliamentary assistant to Members of the Luxembourg and European Parliament. I have been the Executive Director of Alzheimer Europe since 1996 where I supervise the involvement of the organisation in a number of Innovative Medicines Initiative and Horizon 2020 projects.