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## Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement)

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### ABSTRACT

This paper reflects Alzheimer Europe's position on PPI (patient and public involvement) in the context of dementia research and highlights some of the challenges and potential risks and benefits associated with such meaningful involvement. The paper was drafted by Alzheimer Europe in collaboration with members of INTERDEM and the European Working Group of People with Dementia. It has been formally adopted by the Board of Alzheimer Europe and endorsed by the Board of INTERDEM and by the JPND working group 'Dementia Outcome Measures - Charting New Territory'. Alzheimer Europe is keen to promote the involvement of people with dementia in research, not only as participants but also in the context of PPI, by generating ideas for research, advising researchers, being involved in consultations and being directly involved in research activities. This position paper is in keeping with this objective. Topics covered include, amongst others, planning involvement, establishing roles and responsibilities, training and support, managing information and input from PPI, recognising the contribution of people with dementia involved in research in this way, promoting and protecting the rights and well-being of people with dementia, training and support, and promoting an inclusive approach and the necessary infrastructure for PPI in dementia research.

### ARTICLE HISTORY

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### KEYWORDS

PPI; people with dementia; research; position paper

### Executive summary

Alzheimer Europe is keen to promote the involvement of people with dementia in research, not only as participants but also in the context of patient and public involvement (PPI) by generating ideas for research, advising researchers, being involved in consultations and being directly involved in research activities. This position paper is in keeping with this objective.

Involvement enables people with dementia to assist in identifying research priorities and the nature of the research to be undertaken, influence the direction and conduct of research, have their voices heard and, in so doing, contribute towards the quality, relevance and ethical conduct of research.

PPI should be planned, incorporated into the study design, budgeted for, documented and monitored.

Funders and ethics committees should expect the full engagement of people with dementia and raise questions if this is not the case. PPI should always be meaningful, rigorous and enhance the research process. It should never amount to tokenism or 'box ticking' (i.e. either not using their input or involving them in an activity that is not needed simply to be able to claim that they were involved).

Researchers should take all necessary measures to ensure the safety and well-being of people with dementia who are contributing towards PPI. However, they should avoid being over-protective/paternalistic and be willing to challenge stereotypes about dementia which may hamper this kind of involvement.

Contributing towards PPI is not the same as being a research participant. Nevertheless, some PPI activities may carry a risk of harm or distress either to the people engaged in PPI or to others. Researchers should therefore check whether they need ethical approval (e.g. for consultation activities or when there may be contact with research participants who have dementia) and whether there are any relevant legal regulations that might be applicable in the country in which the research is being conducted.

Irrespective of whether ethical approval is required for PPI, researchers should ensure that people with dementia understand what the research is about, the role they are being asked to play, the skills or experience needed, any support or training that might be offered and that they are free to withdraw at any time.

All costs incurred as a result of PPI (e.g. travel, accommodation and meals) should be covered and, whenever possible, provided upfront.

The contribution made by people with dementia should be fairly, appropriately and openly acknowledged in a way that is acceptable to the individuals concerned.

### Introduction

#### *A move towards greater involvement and inclusion of people with dementia in research*

In the last few decades, there has been an increasing international emphasis on involving patients, informal caregivers and the general public in various aspects of health care,

including health-related research and policy-making. Such involvement, which goes beyond being a research participant, is often referred to as PPI.

PPI is about carrying out research and developing policies with or by members of the public and patients rather than on or for them as mere participants (INVOLVE, 2012a). This represents a step towards recognition that people have 'a right to voice', with suppression or denial of that voice being considered a form of abuse (Swain, Heyman, & Gillman, 1998). It is a core democratic principle that 'people who are affected by research have a right to have a say in what and how publicly funded research is undertaken' (INVOLVE, 2012b, p.8; Tarpey & Bite, 2014). The inclusion of their voice in the research team also provides a unique perspective 'from the inside' (Simpson & House, 2002).

It was long assumed by many researchers that the accounts of people with dementia were not reliable and, consequently, their voices were not heard, also in the context of research. Over the last decade, experience has shown that many people with dementia can be meaningfully involved in research (Alzheimer Europe, 2011). The growing interest in PPI in the field of dementia research represents a positive step towards the inclusion of people with dementia in matters which are relevant to their lives and recognises the valuable contribution they can make to society.

### **What PPI typically involves**

PPI involves a range of activities, ranging from people with dementia being consulted at various stages of the research or about a specific issue to a more comprehensive involvement as co-researchers playing a key role in the planning and conduct of a research project and sometimes in the data collection and analysis (McNichol & Grimshaw, 2014).

Specific areas in which people with dementia might typically be involved include the identification of ideas for research, prioritisation of studies, assisting with defining the topic and the research questions, contributing towards the ethical debates and implications of the research, the design and management of studies, data collection and interpretation, the dissemination of findings and the development of research-related policy.

People with dementia may be asked to contribute towards PPI in research using a wide variety of research methodologies (e.g. qualitative, quantitative, mixed methods, co-production, co-research and participatory approaches).

PPI may also draw on a range of research methods such as interviews, focus groups, surveys and questionnaires, Delphi rounds, user-led forums, email and Skype consultations. Furthermore, there are variations surrounding the use of these terms and about what the different approaches involve. PPI is therefore an over-arching term which makes it difficult to compare its impact in different studies. Nevertheless, on the basis of a mixed methods study involving Delphi rounds and interviews, consensus was reached that despite the complexities of evaluation, it is feasible to evaluate the impact on some research processes, outcomes and on key stakeholders (Barber et al., 2012).

An important aspect of PPI is co-production which highlights the importance of contributions from different disciplines and from different actors in the field, especially within communities (Durose, Beebeejaun, Rees, Richardson, & Richardson, 2011). This represents a form of empowerment as

it challenges embedded knowledge hierarchies 'of the expert versus the lay subject' and recognises that communication is not 'a one way transfer from a knowing subject to a supposedly ignorant one' (Porter, 2010). Cheffey, Hill, McCullough, and McCullough (2017), for example, refer to the value of the interaction between 'experts by training' and 'experts by experience' (i.e. the people with dementia).

### **The necessity for a position by Alzheimer Europe**

It is essential that PPI is conducted in such a way that it promotes a meaningful and active involvement of people with dementia in research and represents a true partnership between people with dementia, researchers and, when appropriate, policy-makers and other members of society.

There is evidence to suggest that PPI improves the quality, relevance and ethical conduct of research (Edelman & Barron, 2015). Increasingly, it is recognised as 'essential for all stages of high-quality research' (Daveson et al., 2015; Poland et al., 2014). In some countries, it has become a central element of government policy and an ethical requirement for health research (Department of Health, 2005; Iliffe, McGrath, & Mitchell, 2013). Nevertheless, there is very little information about the specific involvement of people with dementia in research (Di Lorito et al., 2016).

A number of studies have been undertaken in recent years which have explored both the benefits and challenges of actively involving people with mental health issues in the research, evaluation, and service improvement agenda (Beresford, 2005; Boote, Barber, & Cooper, 2006). Researchers have a legal and moral obligation to protect not only participants but everyone involved in the research process from harm whilst striving to ensure that the process and outputs of PPI are successful, meaningful and mutually beneficial.

Alzheimer Europe's aim in writing this position paper on PPI and dementia was to reflect on the challenges and potential risks and benefits associated with the meaningful involvement of people with dementia in research conducted by Alzheimer Europe or in collaboration with external researchers. It is also important to the development of dementia-related policies across Europe.

### **Guiding framework**

Alzheimer Europe and its members fully commit to promoting the rights, dignity and autonomy of people living with dementia. These rights are universal, and guaranteed in the European Convention of Human Rights, the Universal Declaration of Human Rights, the International Covenants on Economic, Social and Cultural Rights and Civil and Political Rights, and the United Nations Convention on the Rights of Persons with Disabilities.

This position paper was influenced by these conventions and covenants and, more specifically, by the charters of rights for people with dementia (and their carers) which were developed in Scotland and Ireland (by the Cross-Party Group in the Scottish Parliament on Alzheimer's in 2009 and The Alzheimer Society of Ireland in 2016). The charters emphasise that people with dementia and their carers (family members and friends) have the same human rights as every other citizen and that they face cultural, social and economic barriers, in addition to the impact of dementia, in being able to fulfil these rights. These rights are described in the framework of

the PANEL approach<sup>1</sup> to human rights-based policy and practice endorsed by the United Nations, which covers participation, accountability, non-discrimination and equality, empowerment and legality.

The position paper further complies with the strategic objective of Alzheimer Europe in providing a voice to people with dementia and their carers, making dementia a European priority, promoting a rights-based approach to dementia, supporting dementia research and strengthening the European dementia movement. This, it is stated in the Strategic Plan of 2016–2020, is to be accomplished by ensuring that people with dementia and their carers are full partners in policy development, research and service design and that policies and research for people with dementia and their carers are based on ethical principles.

## Involving people with dementia in research through PPI

### *Determining, planning and involving people with dementia in the research process*

PPI can promote the transparency, validity and legitimacy of research projects. People with dementia can provide unique and valuable experiential knowledge about living with this condition and can provide different perspectives and views on the topic. Knowing that patients and the public have been involved in a particular study may also increase trust and confidence of end-users in the reported findings (Hunn, 2013), hence the need to ensure that such involvement truly adds to the value of the research.

The nature and extent of involvement of people with dementia should be planned, incorporated into the study design, documented and monitored. Reasons for not involving people with dementia should also be documented.

Although PPI may sometimes consist of a one-off activity, there should be an emphasis on the continuous involvement of people with dementia during the life cycle of a particular research project. Attempts should be made to involve people with dementia at the earliest opportunity, which ideally is at the development of a project idea, and in many cases may be before the official start of the project (e.g. to identify and prioritise topics, discuss what might be meaningful outcomes or discuss issues related to the design of the planned project such as the suitability of various methods or whether certain tasks would be too intensive or potentially disturbing for research participants with dementia). Involvement in dissemination activities during and after the end of the project should also be considered.<sup>2</sup>

Any involvement of people with dementia should be meaningful and appropriate. It should not be an afterthought or mere tokenism. For this reason, PPI should be written into the application for research funding and ethical approval (even if ethical approval is not specifically needed for the PPI involvement proposed) and this should include a justification for such involvement and a description of the nature of the proposed activities.

Researchers should take the necessary measures to ensure that the involvement of people with dementia in the research process is conducted in a rigorous and ethical manner. They should ensure that the same scientific standards and ethical considerations applied to every other aspect of the research are equally applied to PPI.

Researchers should ensure that sufficient resources are available for good quality PPI. The costs of PPI should therefore be budgeted for within any project. It should be borne in mind that certain costs, such as for travel, meals and accommodation, will often be for two people (i.e. due to the possible need for assistance with travel or during the meeting, and as the person with dementia might be unable to contribute towards a particular task at some point<sup>3</sup>). There may also be costs for additional nights' accommodation, assisted travel, direct flights and taxis, also for short distances, and for additional time for researchers to prepare and brief people with dementia for their involvement in the research.

Whilst carers often play a valuable role in supporting people with dementia and enabling them to contribute to research through PPI, researchers should ensure that they listen to the voice of the person with dementia and not to that of the carer. It may be helpful for researchers to provide carers with guidance on how to support the person with dementia in a particular study so that carers can facilitate the involvement of the person with dementia, minimise unnecessary interference and feel valued for the support they provide.

Unless specific personal characteristics are required for PPI activities in a particular project (e.g. a recent diagnosis or people with dementia living alone or at a specific stage of the condition), researchers should try to include people with dementia from different social, cultural and geographical backgrounds, as well as with different types of dementia.

PPI must be suited to the ability of each individual to carry out a particular task. The involvement of people with more advanced dementia should not be ruled out. Researchers should explore possible approaches to involving people with advanced dementia, tailor the task where possible to the individual concerned, and ensure that appropriate support is provided and that all the conditions for contributing towards PPI are nevertheless fulfilled (see Section 'Training and support').

As dementia is a condition which typically involves progressive loss of cognitive abilities, a person with dementia may at some point be unable to continue to contribute meaningfully to the study. Researchers should consider how to deal with this in advance in order to protect the well-being of the person with dementia. This issue could be discussed with the person with dementia at the start of his/her involvement (provided that she/he is comfortable doing so).

### *Establishing and respecting roles and responsibilities*

Researchers have legal, ethical, financial and contractual responsibilities, as well as extensive training in research methods, which people with dementia (unless they are or have been researchers) do not have. On the other hand, people with dementia can bring into the whole research process the experience and perspective of having dementia which researchers (with possible exceptions) do not have. This has implications for the relationship between the researchers and the people with dementia and also for the organisation and division of roles and responsibilities.

People with dementia and researchers should strive to promote a relationship based on mutual respect for the contribution that each makes to the research process. PPI should provide an opportunity for reciprocity with people with dementia contributing towards research but also gaining something positive from the experience of participating.

The roles and responsibilities of researchers and people with dementia should be clarified and communicated to all concerned. This should include a clear description of relevant tasks and of any skills or knowledge that might be required. People with dementia must know what is expected of them before being asked to make a decision about any possible involvement. Their ability to undertake the work should be monitored during the research.

People with dementia should be informed that in the context of PPI, they should feel able to share their own views and experience which will not necessarily be the same as those of other people with dementia.

Researchers should maintain overall responsibility and control for management and administrative matters such as funding, hiring personnel, ensuring that deadlines are met and the submission of reports. They should involve people with dementia in activities and decision-making linked to the content of the research (e.g. to the design of the study, the collection and analysis of data and addressing ethical issues) and consider ways to share responsibility and control for this with people with dementia engaged in PPI wherever possible and meaningful.

### **Promoting and protecting the rights and well-being of people with dementia**

People with dementia are potentially vulnerable irrespective of whether their participation consists of being a research participant or is related to PPI. The nature of the protection required and of measures to promote the well-being of those engaged in PPI will depend to a great extent on the nature and extent of their involvement in the research. In most cases, PPI should not require ethical approval including a formal procedure for informed consent and/or a formal assessment of capacity. Nevertheless, researchers have an ethical duty to promote the well-being of people with dementia who contribute towards their study through PPI.

Researchers should ensure that any person with dementia contributing to a research project in any way:

- has received and understood information about the nature of the study and the proposed involvement, and is regularly updated about how the study is progressing and about his/her involvement in it,
- agrees to being involved and does not feel under any pressure to do so,
- is able to carry out the required tasks.

In cases where there is a foreseeable risk of psychological, emotional or physical harm to people with dementia resulting from PPI, researchers should ensure that the people with dementia concerned are informed of and understand that risk.

Special attention should be paid to the possible emotional and psychological impact on people with dementia resulting from those contributing to PPI coming into direct contact with others who are participants in a particular study.<sup>4</sup> This might, for example, occur if they are involved in the process of data collection.

The involvement of people with dementia should be suited to each person's abilities. Special attention should be paid when involving pre-existing groups of people with dementia as the individual members of the group may have

different abilities and needs. It should always be made clear that each member of the group has the right to decide whether or not to participate in a PPI activity.

Appropriate steps should be taken to maximise the potential of each person with dementia to contribute meaningfully to the research project.

Researchers should consider what kind of support (e.g. organisation of travel, accommodation, refreshments, sensory difficulties, mobility or continence problems) might be required to enable each individual to contribute effectively to PPI and minimise the risk of any harm or distress occurring before, during or after their involvement (see also next section on training and support).

Special measures of protection (e.g. with regard to privacy and confidentiality) should be considered in situations or in relation to specific tasks where having dementia might mean that a particular person is potentially vulnerable. However, paternalistic attitudes and behaviour, including blanket measures applied to all people with dementia contributing to PPI, should nevertheless be avoided.

People with dementia should be given the opportunity to be supported by a person of their choice (e.g. for practical assistance to facilitate their participation or to help them to contribute towards discussions and activities). This could be any person whom they feel would be best able and willing to provide the support they need (e.g. a relative, friend, volunteer or researcher).

People with dementia, and their carers where appropriate, should be asked if they would like the contact details of a person whom they can talk to, should they have any questions or concerns linked to their involvement in a particular study.

Each person involved in research should treat others with respect and be treated in a similar manner. This involves respecting the right of other people to have opinions and perspectives which may differ from one's own. Differences of opinion may arise between researchers, between people with dementia and between people with different stakes in the study and different viewpoints. A procedure should be established to address possible disagreements and complaints.

Whilst ethical approval (including the need for formal informed consent and an assessment of capacity) is unlikely to be required for most PPI, researchers should check whether there are any legal obligations or ethical or governance approvals needed in the countries in which they are conducting their research, and if so take the necessary steps to comply with such requirements.

Researchers should ensure that the term 'PPI' is not used to describe or camouflage activities which actually constitute participation in research, thereby unjustifiably side-stepping the need for ethical approval and formal informed consent.

### **Training and support**

Most people with dementia are not experienced researchers and therefore lack the knowledge about different designs and different methods of data collection and analysis that researchers have. They may also be unfamiliar with the underlying assumptions and philosophies surrounding research. It is therefore important that researchers consider what kind of training and support might be beneficial and empower people with dementia to fulfil their PPI role in the research and that they are trained in how to conduct PPI with people with dementia.

People with dementia should be provided with information about the research project as a whole (i.e. a lay description) and specific information linked to the proposed involvement (e.g. why they have been invited to take part, what they might be asked to do and practical information linked to their possible involvement).

Researchers should ensure, wherever possible, that all relevant and necessary documentation used for PPI is dementia-friendly.<sup>5</sup> Scientific jargon and abbreviations should be avoided as far as possible (also in discussions) and lengthy or dense text as well as small print should be avoided. If documentation cannot be rendered dementia- and lay-friendly, researchers should consider whether support can be provided to those who have volunteered to be involved. If this is also not possible, despite all reasonable attempts having been made, the involvement of people with dementia in that particular activity should be reconsidered.

Researchers should bear in mind that some people with dementia are likely to need more time to prepare for and carry out tasks. Documentation should be sent to people with dementia involved in PPI activities for a study in advance (e.g. at the latest 2 weeks before the planned involvement) so that they have time to go through it, seek any necessary clarification or support and prepare for the task.

Whenever possible, researchers should offer to go through any research materials and provide a briefing or explanations before the meeting, either face to face or by phone or email, depending on the preferences of the people with dementia concerned and the resources available.

PPI is rapidly becoming an ethical requirement for good dementia research but such involvement must first and foremost have the potential to benefit a particular research project. Not everyone has the skills, motivation and aptitude to contribute effectively towards PPI or can acquire these through training. People with dementia must be carefully selected in the interest of their own well-being and that of the research (e.g. by checking that they have or can acquire any skills needed, are sufficiently motivated, have or can be provided with relevant support and understand what is involved).

Relevant and appropriate training should be offered to people with dementia if and when required. When organising such training, attention should be paid to the capacities and skills of the people with dementia who have volunteered, the complexity of language used and how this can be moderated, the timing and frequency of the training and the possible need to refresh the training at some point.

Steps should be taken to help people with dementia to keep track of their ongoing involvement and how this fits in with the overall research project (e.g. a short record or reminder of what they have done so far, a brief progress report at regular intervals) so as to promote continuity for them and others involved in the project.

Researchers should be trained in how to conduct PPI and how to communicate with people with dementia,<sup>6</sup> not only in order to ensure the effective and meaningful involvement of people with dementia but also to promote a positive, friendly and respectful environment for PPI.

Researchers should carefully select venues for PPI and consider issues that may be important for people with dementia such as the location, lighting and signposting. If venues and staff at these venues have no prior experience in working

with people with dementia, then the researchers should organise training.

### ***Managing information and input resulting from PPI***

PPI will often result in other people (e.g. researchers or event organisers) becoming aware that a person has dementia and/or in researchers finding out information, sometimes of a fairly personal nature, about the person with dementia or other people. Issues related to confidentiality, privacy and ownership of information are therefore relevant to the ethical conduct of PPI.

Researchers should clarify and document how they will involve and use input from people with dementia in a particular study. If it is not possible to involve people with dementia in the identification of how output will be used, researchers should try to be open to suggestions from people with dementia on how to improve or adapt it.

People with dementia who are involved in PPI should be given the opportunity to check through information that they have provided to see whether it has been recorded, interpreted and reported to their satisfaction.

If people with dementia disagree with the interpretation or reporting of the PPI contribution they have made, their point of view or objection should also be reported.

All or parts of information provided by people with dementia for PPI should be anonymised if requested by the person with dementia.

Researchers or organisations carrying out PPI on behalf of other researchers should monitor how the resulting information is used and reported, and ensure that those providing it, as well as they themselves, are properly acknowledged.

If such researchers or organisations feel that the information is being inaccurately reported or inappropriately used, they should inform the researchers concerned and take measures to ensure that it is withdrawn from the study.

People with dementia who have contributed towards PPI should be informed about the final results of the research even if this is some time after their involvement (unless they have stated that they do not wish to be informed). As with all documentation, this should be in a dementia-friendly format (as should all information provided during the course of the study).

### ***Recognition and acknowledgement of the contribution made by people with dementia***

In everyday life, a person's effort or contribution is often acknowledged by a private remark or comment, a public declaration, an award, a token gesture and/or some form of payment. People with dementia often contribute towards research out of altruistic motives or through a sense of solidarity towards fellow citizens. Very few are paid for their contribution, unlike researchers who tend to be funded through research grants or receive a salary for their efforts. Researchers are also formally recognised by the research community for their achievements through the publication of their work in peer-reviewed scientific journals.

Researchers should consider appropriate and meaningful ways to acknowledge the contribution made by people with dementia to their study (in addition to regularly saying 'thank you').

People with dementia who have contributed towards an article for publication in a peer-reviewed journal should be acknowledged in the article (either as co-author or in the acknowledgements section, depending on the nature of their contribution) unless they prefer to remain anonymous.

If one or more people with dementia in a group contributing to a research publication do not wish to have their names acknowledged, any acknowledgement should be in the name of the group.

If funds are available for the payment of external experts (e.g. fees to attend a meeting or daily allowances) in connection with PPI, such funds should be offered to people with dementia on an equal basis.

Researchers should try to cover any out-of-pocket expenses incurred by people with dementia linked to participation in their research and try to ensure that people with dementia claim for all expenses to which they are entitled.

The policy for reimbursements should be communicated to people with dementia in advance and details should be available on request at any time. Reimbursements should be made promptly and administrative procedures should be straightforward and kept to the minimum.

### **Promoting an inclusive approach to research and creating the necessary infrastructure for PPI in dementia research**

Alzheimer Europe and its member associations aim to contribute actively towards the development of an inclusive approach to dementia research and policy development by promoting PPI initiatives and encouraging reflection on how best to achieve meaningful and effective PPI. The establishment and support of local and national working groups of people with dementia will be helpful in this respect.

Alzheimer Associations should, together with people with dementia and carers, try to facilitate the necessary link between people with dementia (and carers where appropriate) and researchers to enable a collaborative approach to research through PPI.

Researchers should seek to involve Alzheimer associations as projects partners, who together with people with dementia and carers are well placed to promote the objectives and relevant findings of research to wider society (e.g. to other people with dementia, the general public, policy-makers and health care providers).

Academic institutions, organisations funding research and ethics committees should promote an infrastructure and environment that is conducive to the meaningful and effective involvement of people with dementia in the research process.

People with dementia should be involved in discussions and on ethics committees addressing issues related to PPI.

### **Conclusions**

This position paper has highlighted several important issues which we feel must be addressed whenever people with dementia are asked to contribute towards research as PPI representatives. The growing awareness of the importance of PPI for dementia research will undoubtedly lead to more opportunities for people with dementia to contribute towards society by helping improve the quality, relevance and ethical conduct of dementia research. Whilst researchers will undoubtedly benefit from this, they will also be faced with

new challenges (e.g. how to give people with dementia an equal opportunity to be involved, how to reach a diverse group of people, how to provide the necessary support and how to maximise the potential of people with dementia to contribute towards research). We welcome the increased attention being paid to PPI in dementia research and encourage researchers in all domains (e.g. psycho-social, biomedical, clinical trials and care-related) to seize the opportunity and to further reflect on and improve the way that PPI is conducted in the field of dementia.

### **Adoption and Endorsement of the Paper**

Approved and adopted by the Board of Alzheimer Europe on 27 February 2017 in Luxembourg. Endorsed by the INTERDEM Board (see [www.interdem.org](http://www.interdem.org)) members: Prof. Dr Myrra Vernooij-Dassen (Chair), Radboud University Nijmegen Medical Centre; Prof. Dr Esme Moniz-Cook (Founder Chair, now Co-chair), University of Hull; Associate Prof. Iva Holmerová, Centre of Gerontology, Prague; Associate Prof. Dr Rabih Chattat, University of Bologna; Prof. Frans Verhey, Maastricht University, Dr Franka Meiland, University Medical Center Amsterdam, Dr Marjolein de Vugt, Maastricht University, Prof. Martin Orrell, University of Nottingham and Dr Manuel Franco Martin, Hospital Complex of Zamora.

Endorsed by the JPND working group "Dementia Outcome Measures - Charting New Territory", <http://www.neurodegenerationresearch.eu/wp-content/uploads/2015/10/JPND-Report-Fountain.pdf>,

### **Notes**

1. Please see Alzheimer Scotland and the Cross-Party Group in the Scottish Parliament on Alzheimer's (2009) for details.
2. Please see McNichol and Grimshaw (2014) for more information.
3. Please see also DEEP guidelines (2013a,b) on this issue.
4. Please see guidance from Health Research Authority/INVOLVE (2016) on this issue.
5. Please see publications (details in the references section) by the Dementia Engagement and Empowerment Project (DEEP) on writing dementia-friendly information and consulting with people with dementia about written documents
6. Please see the core principles developed by the Scottish Dementia Working Group (2014) which provide some guidance on how to involve people with dementia in research, some of which is also applicable to PPI.

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### **References**

- Alzheimer Europe. (2011). *The ethics of dementia research*. Luxembourg: Binsfeld.
- Alzheimer Scotland and Cross-Party Group in the Scottish Parliament on Alzheimer's. (2009). *Charter of rights for people with dementia and their carers in Scotland*. Retrieved from <http://www.dementiarights.org/charter-of-rights/>

- Barber, R., Boote, J.D., Parry, G.D., Cooper, C.L., Yeeles, P., & Cook, S. (2012). Can the impact of public involvement on research be evaluated? A mixed methods study. *Health Expectations*, 15(3), 229–241.
- Beresford, P. (2005). Developing the theoretical basis for service user/survivor-led research and equal involvement in research. *Epidemiologia e Psichiatria Sociale*, 14(1), 4–9.
- Boote, J., Barber, R., & Cooper, C. (2006). Principles and indicators of successful consumer involvement in NHS research: Results of a Delphi study and subgroup analysis. *Health Policy*, 75(3), 280–297.
- Cheffey, J., Hill, L., McCullough, C., & McCullough, C. (2017). "Can I facilitate a project when my memory lets me down?": The challenges and rewards of co-producing a "living well with dementia" course. *FPOP Bulletin*, 137, 19–25.
- DEEP. (2013a). *Tips for organisations wanting to consult people with dementia about written documents*. Retrieved from <http://dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Consulting-about-written-documents.pdf>
- DEEP. (2013b). *Writing dementia-friendly information*. Retrieved from <http://dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Writing-dementia-friendly-information.pdf>
- Daveson, B.A., de Wolf-Linder, S., Witt, J., Newson, K., Morris, C., Higginson, I.J., & Evans, C.J. (2015). Results of a transparent expert consultation on patient and public involvement in palliative care research. *Palliative Medicine*, 29(10), 939–949.
- Department of Health. (2005). *Research governance framework for health and social care* (2nd ed.). London: Author.
- Di Lorito, C., Birt, L., Poland, F., Csipke, E., Gove, D., Diaz-Ponce, A., & Orrell, M. (2016). A synthesis of the evidence on peer research with potentially vulnerable adults: How this relates to dementia. *International Journal of Geriatric Psychiatry*, 32(1), 58–67.
- Durose, C., Beebeejaun, Y., Rees, J., Richardson, J., & Richardson, L. (2011). *Connected communities: Towards co-production in research with communities*. Swindon: AHRC.
- Edelman, N., & Barron, D. (2015). Evaluation of public involvement in research: Time for a major rethink. *Journal of Health Services and Research Policy*, 21 (3), 1–4: doi:10.1177/1355819615612510
- Health Research Authority/INVOLVE. (2016). *Patient and public involvement in research and research ethics committee review*. Retrieved from <http://www.invo.org.uk/wp-content/uploads/2016/05/HRA-INVOLVE-updated-statement-2016.pdf>
- Hunn, A. (2013). *Survey of the general public: Attitudes towards health research*. London: NHS, Health Research Authority.
- INVOLVE. (2012a). *What is public involvement in research?* Retrieved from <http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/>
- INVOLVE. (2012b). Briefing notes for researchers: involving the public in NHS, public health and social care research. Eastleigh: INVOLVE.
- Iliffe, S., McGrath, T., & Mitchell, D. (2013). The impact of patient and public involvement in the work of the Dementias & Neurodegenerative Diseases Research Network (DeNDRoN): Case studies. *Health Expectations*, 16(4), 351–361.
- McNichol, E., & Grimshaw, P. (2014). An innovative toolkit: Increasing the role and value of patient and public involvement in the dissemination of research findings. *International Practice Development Journal*, 4(1), 1–14.
- Poland, F., Mapes, S., Pinnock, H., Katona, C., Sorensen, S., Fox, C., & Maidment, I.D. (2014). Perspectives of carers on medication management in dementia: Lessons from collaboratively developing a research proposal. *BMC Research Notes*, 7, 463–473.
- Porter, L. (2010). *Unlearning the colonial cultures of planning*. Surrey: Ashgate.
- Scottish Dementia Working Group. (2014). Core principles for involving people with dementia in research: Innovative practice. *Dementia*, 13 (5), 680–685.
- Simpson, E., & House, A. (2002). Involving users in the delivery and evaluation of mental health services: Systematic review. *British Medical Journal*, 325(7375), 1265–1268.
- Swain, J., Heyman, B., & Gillman, M. (1998). Public research, private concerns: Ethical issues in the use of open-ended interviews with people who have learning difficulties. *Disability and Society*, 13(1), 21–36.
- Tarpey, M., & Bite, S. (2014). *Public involvement in research applications to the National Research Ethics Service: Comparative analysis of 2010 and 2012 data*. Eastleigh: INVOLVE.
- The Alzheimer Society of Ireland. (2016). *A charter of rights for people with dementia*. Retrieved from <https://www.alzheimer.ie/getattachment/About-Us/Policy/Human-Rights/A-Charter-of-Rights-for-People-with-Dementia/Charter-of-Rights-for-People-with-Dementia.pdf.aspx>