



# Barriers and Facilitators to conducting a Patient and Public Involvement (PPI) project with family carers of people with dementia



Áine Teahan<sup>1</sup>, Gerard Fealy<sup>1</sup>, Amanda Phelan<sup>1</sup>, Diarmuid O'Shea<sup>2</sup>,  
Eilish McAuliffe<sup>1</sup>, Liam O'Sullivan<sup>3</sup>, Sandra McCarthy<sup>3</sup>, Attracta Lafferty<sup>1</sup>

<sup>1</sup> UCD School of Nursing, Midwifery and Health Systems, Dublin; <sup>2</sup> St Vincent's University Hospital Group, Dublin;  
<sup>3</sup> Care Alliance Ireland, Dublin



## 1. Introduction

A formalised and widespread approach to Public and Patient Involvement (PPI) is a relatively new concept in Ireland (Irish Health Research Forum 2015). PPI occurs when members of the public work in partnership with researchers to identify priorities for research, in planning and managing research studies, as well as in summarising, distributing, sharing, and putting results into practice. PPI in research can help to improve research design and quality, while ensuring that it remains relevant to the user group (INVOLVE, 2014), however creating an effective PPI climate can be challenging.



## 2. Overall Aim

The overall aim of this paper is to highlight the barriers and facilitators related to PPI when conducting participatory action research with an 'Enhancing Carers' Resilience' (EnCaRe) network of family carers of people with dementia. The EnCaRe network are currently designing a programme that aims to enhance resilience among family carers of people with dementia.

## 3. Barriers and Facilitators

### Ethical Issues

#### Barriers

- Use of PPI language (e.g. sample, participants, collaborators versus co-researchers, peer-researchers, etc.)
- Ethics committees' lack of awareness of PPI protocol



#### Facilitators

- Consultations with expert advisory groups (e.g. INVOLVE UK, ethics committees, other PPI researchers)
- Consult available PPI documentation (e.g. PPI guidelines, evidence-based articles)

### Recruitment of Family Carers of People with Dementia

#### Barriers

- Communicate the aim of PPI research to collaborators
- Recruitment of a representative PPI family carer group (e.g. age, gender, relationship to the person with dementia)



#### Facilitators

- Build strong relationships with relevant carer organisations and collaborators (e.g. charities, NGOs, advocacy groups etc.)
- Develop an effective communication strategy to ensure that recruitment is far-reaching and that potential PPI members understand their role

### Family Carers as Co-Researchers

#### Barriers

- Establish and maintain an EnCaRe network
- Family carers have limited resources and time due to caregiving responsibilities
- Limited budget to facilitate carers to attend network meetings



#### Facilitators

- Extend inclusion criteria to include former as well as current carers
- Ensure the project budget considers practical costs (e.g. travel expenses for family carers)

### Support for Co-Researchers

#### Barriers

- Deal with sensitive topics that arise during meetings
- Management of PPI members' expectations



#### Facilitators

- Develop a support protocol around sensitive topics
- Foster a supportive group dynamic
- Be transparent and realistic around expectations

## 4. Conclusions

PPI research projects involving co-researchers necessitate having effective and supportive structures in place to ensure that barriers are overcome and participatory action research projects can be conducted effectively. It is important that PPI groups such as family carers of people with dementia are encouraged, supported and facilitated to engage in all aspects of the research design so that they can integrate successfully into the research process.

## 5. References

Irish Health Research Forum (2015) Document on: Public and Patient Involvement (PPI) in Research [www.ihrf.ie](http://www.ihrf.ie)  
INVOLVE UK [www.invo.org.uk](http://www.invo.org.uk)

## 6. Contact Details

This study is being undertaken as part of a 3 year HRB-funded research project entitled 'Towards resilience in family caregiving for people with dementia'. Please email [familycarersdementia@ucd.ie](mailto:familycarersdementia@ucd.ie) for further information.