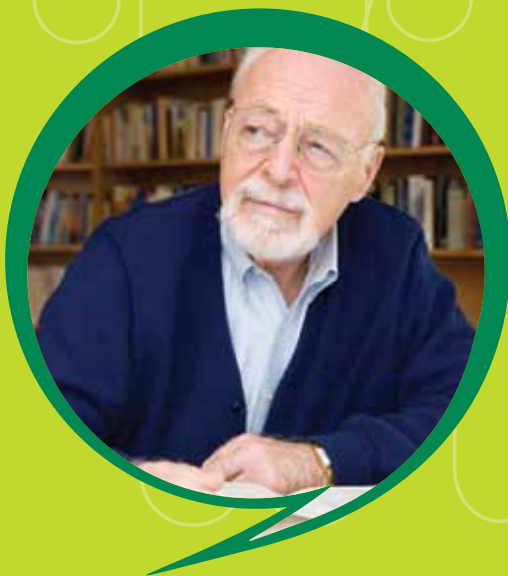


# Involving People

## An internal evaluation of infrastructure support for active involvement in health and social care research in Wales

By Carol Porteous and David M Rea, with Bryan Collis<sup>1</sup>



## Lay Summary

<sup>1</sup> Carol Porteous is Research Associate within the School of Health Science, Swansea University, Dr David M Rea and Dr Bryan Collis are Associate Directors of Involving People / Cynnwys Pobl.

# Lay Summary

## Acknowledgements

We would like to acknowledge the time and energy given by the people who responded to our enquiries and participated in this evaluation. In particular, we thank the members of the evaluation team: Jan Davies, Martyn Hooper, Alan Meudell and Eiddwen Thomas.

While their contribution was invaluable to us, the authors take responsibility for the contents of this report.

Thanks to go to Natalie Simon for comments on an earlier version.

By February 2009  
the network had 173  
members, 118 of which were  
patients, which was well  
above target.



## Background

Involving People was set up in 2006 as part of the Clinical Research Collaboration Cymru (CRC-Cymru), to enable the effective involvement of patients, carers and service users in health and social care research in Wales.

## Aim of the Evaluation

The evaluation was conducted during 2008 to assess whether, and to what extent, Involving People had achieved its goals to date and how these had been achieved. This information was used to make recommendations for the future.

## How the evaluation was conducted

A team of four patients, carers and service users was recruited from the Involving People network. This team became actively involved in planning, designing and carrying out the evaluation. They also examined the Involving People work plans and activity reports.

Patients, carers and service users on the Involving People network were asked if they would like to be interviewed and 24 responded. Of these, eight were selected to be interviewed and 12 were invited to discuss issues in a focus group.

100 people on the CRC-Cymru mailing list were asked to complete a web based questionnaire. 20 people completed the questionnaire and, of these, six were interviewed.

## The Results

Involving People met its target of 50 patients, carers and service users on the network by December 2008. By February 2009 the network had 173 members, 118 of which were patients, which was well above target.

Overall, 168 referrals to involvement activities have occurred, with 60 selected to get involved in funded projects. People have been referred to 32 research activities.

The interviews with patients, service users or carers suggest that a variety of barriers, motivations and opportunities exist for patients, carers and service users to get involved in research. Barriers discussed included the use of jargon and practical issues such as finding carers and getting transport to meetings. The benefit of involvement is linked with a motivation to improve services.

Each network member interviewed had differing expectations of their involvement and what they wanted to get out of being involved. They also had differing views of the interaction between themselves and the researchers. Issues about expectations and interaction are linked to strong beliefs that there are responsibilities and roles that need to be fulfilled by researchers and funding bodies. At the time of the evaluation, network members reported limited opportunities to become involved and

In conclusion, Involving People has met its work targets and both researchers and patients, service users and carers involved, report beneficial outcomes from the involvement.



even when they were, or had been, involved they often found progress was slow. Patients, carers and service users also found the structures in which Involving People works complicated and confusing and the context of research difficult to understand. This is important because in order to have meaningful engagement in research projects, network members must understand the research structure and how different elements relate to each other.

Despite these difficulties in understanding the structure and context of research, network members were positive about continuing their involvement and thought Involving People was doing what it set out to do.

Researchers too reported the barriers and benefits of involving patients, carers and service users in research. Researchers have limited budgets and question the value for money of involving people in research. There is also the perception that patients, carers and service users are there for their own agenda and not for the benefit of the research. This relates to the interaction between researchers and service users and the expectations of both. Researchers also felt they had to meet the expectations of patients, carers and service users and found this challenging.

Some researchers reported that it was beneficial to involve people as it prompted them look at issues within the projects from a different perspective.

### Conclusion

In conclusion, Involving People has met its work targets and both researchers and patients, service users and carers involved, report beneficial outcomes from the involvement. There were, however, significant barriers for all parties, which need to be addressed in order for involvement to be more effective.

### Recommendations

The findings and initial recommendations were discussed with the Involving People Advisory Group in March 2009 and further recommendations made as a result of these discussions. The recommendations included:

- Joint training for both researchers and network members, where individuals can share expectations and motivations.

- Because researchers sometimes question the value and purpose of involvement, Involving People needs to build on its relationships with research networks.
- New recruitment procedures for the Advisory Group were suggested so that researcher concerns would be addressed. This recommendation was implemented in time for the recruitment of replacement members of the Advisory Group during summer 2009.
- Involving People to hold meet and greet sessions every quarter for newly recruited network members to help them understand the purpose of Involving People, the research structure and how different elements within the structure relate to each other.
- Monitoring of the training undertaken by network members is needed to ensure they are prepared for their involvement.
- Devise a procedure for giving feedback to network members on their involvement.
- An event should be organised to recognise the time and effort of Involving People network members.

**The full evaluation report can be found on the 'About Us' page of the Involving People website: [www.involvingpeople.org.uk](http://www.involvingpeople.org.uk)**

**Alternatively, contact Dr David M Rea, Centre for Health Economics, and Policy Studies, School of Health Science, University of Swansea, Singleton Park, Swansea, SA2 8PP, United Kingdom**

**<http://www.healthscience.swan.ac.uk/>**

**tel (0044) 01792 295314  
fax (0044) 01792 295643**

**[d.m.rea@swansea.ac.uk](mailto:d.m.rea@swansea.ac.uk)**