Preconceptions, power and position: researcher reflections on public involvement in research

Katherine Pollard, David Evans, Jane Dalrymple Margaret Miers, Pam Moule, Judith Thomas



Public involvement in UK health and social care (H&SC) research

- DH (2005) service users/carers/public should be actively involved in 'design, conduct, analysis and reporting of research'
- NIHR increasingly requires evidence of active public involvement when commissioning research
- INVOLVE established in 1996 to promote public involvement in H&SC research (renamed in 2003)



Public involvement in H&SC research at UWE

Service Users and Carers in Research committee (SUCIR) in the Faculty of Health and Life Sciences:

- Established in September 2008
- Formal launch in June 2009



Three examples of UWE projects with public involvement

- National evaluation of Pacesetters local initiatives for improving health status
- Engagement in the co-production of knowledge for knowledge exchange in health and social care
- Development of an attitude scale to measure userresponsiveness in an interprofessional context



Researcher attitudes to public involvement in H&SC research

- Some health and social care professionals generally opposed to public involvement in H&SC delivery (Campbell 2001, Rowe & Shepherd 2002, Florin & Dixon 2004, Nathan et al 2006)
- Limited research about public involvement in HSC research (Staley 2009)
- Little known about underlying researcher attitudes found to be complex in 1 study (Thompson et al 2009)



UWE researchers' reflections

- Six UWE researchers provided written answers to three questions concerning:
 - their own preconceptions about the topic
 - their perceptions of relevant power issues
 - the positions they adopt to optimise research outputs
- Other issues also identified in their replies



Preconceptions

- Extent of public involvement
 - Lack of awareness of spectrum of involvement, thinking in terms of consultation
 - Issues of control; who makes decisions?
- What is research?
 - Understanding of issues
 - Assumption of superior knowledge; whose knowledge base is valued?
 - Research as a defined process



Power

- Complexity
 - Traditional power balance
 - Status and hierarchies
 - Enabling power
- Limited power of academics
 - Wider political agendas
 - Organisational priorities/constraints



Positions

Personal level

- More likely to ensure own contribution
- Tailor things to service users
- Line of least resistance

Organisational level

- Focus on institutional systems
- Creating opportunities for involvement



Logistics

- Added layer of complexity
- Hard work
- Time consuming
- Resource issues
- Is involvement sustainable?



Other key points

- Researcher self-awareness
 - gap between commitment and practice
 - not taking things for granted, e.g. access to resources
- Representativeness what does this mean?
- Use of narrative methods



Conclusions

- Need to question assumptions:
 - what does involvement actually entail?
 - whose knowledge matters?
 - what is research?
- Power balance
- Logistics
- Need for reflection and self-awareness



End note

 One reflection on the experience of working with SU1 and C1 is that it was fun, enjoyable, enlightening. (R3)



References

- Campbell P (2001) Psychiatric Bulletin 25 87-88
- DH (2005) Research Governance Framework for Health and Social Care DH, London
- Florin D, Dixon J (2004) British Medical Journal 328 159-161
- Nathan S et al (2006) Journal of Health Organisation and Management 20 551-559
- Rowe R, Shepherd M (2002) Social Policy & Administration
- Staley K (2009) Exploring Impact: Public Involvement in NHS, Public Health and Social Care Research INVOLVE, Eastleigh
- Thompson J et al (2009) Health Expectations 12 209-220

