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 user-responsiveness in an interprofessional context
Researcher attitudes to public involvement in H&SC research


• 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

• Florin D, Dixon J (2004) British Medical Journal 328 159-161
• Rowe R, Shepherd M (2002) Social Policy & Administration