

Bridging the gap between good practice principles and research study realities.

Using case studies to build descriptors of the public involvement role in the design and conduct of health research, and understand how research contexts constrain and enable involvement opportunities

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Session outline

- Background to research project
- Context factors
- Clarification of purpose, aims and tasks
- Development of role description
- Sources of experience

Background to research project

- Aims
 - To explore, describe and understand involvement in three case studies
 - To reflect on data in relation to issues in the literature and personal experience
- Case study research topics
 - Rheumatology, domestic violence, oral health
- Qualitative and ethnographic approach

Data collection and analysis

- Observation (72 hrs)
- Interviews (n=31)
- Documents (n=58)
- Field notes and reflective diary
- Data collected over 15, 13 and 9 months
- Between Jan 2012-April 2013
- Initial inductive analysis
- Documentary analysis based on Prior (2008)
- Subsequent analyses drew on literature

Context factors

1. Knowledge location as a key determinant of the scope and purpose of involvement
2. Environmental factors (or research factors)
3. Local factors (or involvement factors)

Environmental factor 1

Field of research

1. Health topic/s
2. Academic , medical and scientific background of researchers
- 3. Complexity of knowledge base**
- 4. Research design/study type and complexity¹**
- 5. Funding body¹**

1 – From Ennis and Wykes (2013)

Environmental factor 2

Proximity or distance

- 1. Between research questions and issues of importance to patients/users**
- 2. Between researchers and study participants**
- 3. Between researcher discipline and service provider staff discipline**
- 4. Between researcher office base and research study site or sites**

Environmental factor 3

Patient/service user

- 1. How seriously a health condition affects the person**
- 2. Short or long-term impact on the person**
- 3. Use of services/need for care over time**
- 4. Third sector organisations and groups**

Local context factors

- Leadership
- Culture of involvement
- Policies for involvement
- Support and training
- Resources – time and money

Purpose and aims

- Scope and purpose of involvement determined by knowledge location
 - Health services research
- Suggesting distinction between
 - Social and political purposes
 - Substantive purposes
- May be both in health services research

Focus on tasks and role

- Clarify purpose/s of involvement
- Identify involvement tasks
- Develop involvement role
 - To support research partner understanding
 - Allow role refinement and development

Tasks in design and conduct of health services research



Tasks in research design & planning

- Make sure the right research is being done in the right way
 - **Importance of priorities and research questions**
 - **Potential benefits**
 - **Are the right things being measured or counted?**
 - **Are documents clear and accessible?**
- Make sure involvement plans are clear & funded
- Giving support for funding bids and ethics applications – providing legitimacy

Tasks in the conduct of research 1

Consider the needs of potential participants

- Aims, risks and benefits of research
- Treatments, procedures, interventions given
- Samples or information being collected
 - **Ethical, reasonable, acceptable**
 - **Clear communication – simple words/language**
 - **Written information – clear, accessible, appropriate and timely**
 - **Questionnaires and forms easy to fill in**
 - **Would you do what is being asked?**

Tasks in the conduct of research 2

- Recruitment and retention
 - **When, where and how to approach potential participants and participants**
 - **How best to keep in touch**
- Data collection
 - **When and where to collect data**
 - **Pilots of interviews and/or questionnaires**
 - Question order, clarity, time, practicalities
 - **Collecting data**
- Analysing data – patient/user/carer perspective

Tasks in dissemination

- Identify findings that are of interest to participants/patients/service users/carers
- Encourage researchers to
 - Give participants feedback about study progress and findings
 - Share findings with patient and user groups/organisations and health professionals
 - Think about how research might change treatment and care
- Help to present/share findings at meetings, conferences

Involvement role

- Based on personal experiences – experiential expertise
- To think about being in a participant's shoes
- To think about wider benefits for patients, service users and carers (even though we cannot represent them)
- To think about researcher assumptions/ideas
 - Speak up if they don't make sense
 - Speak up if something important is missing
- To let researchers know what we don't understand
- To help researchers make good use of our experience, knowledge and skills and do good research

Sources of experience or skill

Experiential
expertise

1. Having a health or
life 'problem'

2. Using health or
social care services

3. Having a distinct
perspective

Additional
expertise

4. Experience of
involvement in
research

5. Experience of doing
research

6. 'Other' life
experience

Thank you

Prior, L. (2008) Repositioning Documents in Social Research. *Sociology* 47(2), 821-836

Ennis, L. and Wykes, T. (2013) Impact of patient involvement in mental health research: longitudinal study. *BJPsych* [online] [Accessed 27/09/2013]

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