User Involvement in Research

- What Is It?
- The Value of It
- How To Do It?
  a) At what stage of research
  b) Continuum of user involvement
  c) Good practice issues
- Support for it
- When to do it
- Vision for the Future
User Involvement in Research

What is it?

- Giving service users a voice in the research process
- Using “lived experience” to inform the research process
- Moving users from being objects of research to active participants in it
- Emancipatory approach of disabled people, older people have power to determine research needs, process and purpose
User Involvement in Research

The value of it

- Expertise of users improves research process
- More chance of research professionals getting it right
- Users should have stakeholders’ rights
- User participation leads to user ownership
- User Involvement makes research process inclusive of marginalised people
- Equality principles
User Involvement in Research

How to do it?

What Stage of Research

The Research Process

1. Who identifies and defines the issue or topic to be studied?
2. Who identifies and defines the hypothesis to be tested and/or the questions to be asked?
3. Who determines the methodologies to be used?
4. Who undertakes the research?
   • Who applies the methodologies/asks the questions?
   • Who decides what, and how, to record the responses?
5. Who collates and interprets the data?
6. Who decides what conclusions should be drawn?
7. Who decides how to present the conclusions?
8. Who draws the lessons for policy and practice?

Who follows through (in Belbin terms, “completes and finishes”) to see action results? (Beresford and Evans, 1999)
User Involvement in Research

How to do it?

<table>
<thead>
<tr>
<th>Mode of Participation</th>
<th>Nature of User Involvement</th>
<th>Relationship Between Research and Users</th>
</tr>
</thead>
<tbody>
<tr>
<td>Co-option</td>
<td>Token: representatives are chosen, but no real action</td>
<td>On</td>
</tr>
<tr>
<td>Compliance</td>
<td>Tasks are assigned, with incentives; researchers decide agenda and direct the process</td>
<td>For</td>
</tr>
<tr>
<td>Consultation</td>
<td>Users’ opinions asked, researchers analyse and decide on a course of action</td>
<td>For/with</td>
</tr>
<tr>
<td>Co-operation</td>
<td>Users work together with researchers to determine priorities; responsibility remains with researchers for directing the process</td>
<td>With</td>
</tr>
<tr>
<td>Co-learning</td>
<td>Users and researchers share their knowledge to create new understanding and work together to form action plans with researcher facilitation</td>
<td>With/by</td>
</tr>
<tr>
<td>Collective action</td>
<td>Users set their own agenda and mobilise to carry it out, in the absence of outside researchers or facilitators</td>
<td>By</td>
</tr>
</tbody>
</table>

(Source: Truman and Raine 2001)
User Involvement in Research

How to do it?

Good practice issues

- Meeting Access Needs
- Costs and reimbursements of users
- Involvement from the start
- Supporting and training for users
- Networking with other initiatives
User Involvement in Research

Support for It

- Further contacts and reading
- Websites

Involve
SCIE
Shaping Our Lives

Emancipatory Approach

Colin Barnes
Jenny Morris
Michael Oliver
Peter Beresford
User Involvement in Research

When to do it

• Any research (including rct’s!)

But Particularly -

• Qualitative Research

• Scoping and Exploring Users’ Issues

• Research and Evaluation Informing Practice which is evidence based

• Service evaluation – Best Value Reviews
User Involvement in Research

The Vision for the Future

- Users informing all research
- User controlled research valued equally with other forms
- Users’ real “lived” experience valued in service planning, delivery and evaluation
- Service evaluation led by users
- Professional researchers acting as allies and advisers to users in research process