Working Collaboratively with Service Users and Carers on Mental Health Nursing Research

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Who are the service users?

• Depends what you are researching

• Context specific

• Students? Staff? Patients? Public?
What do we mean by involvement?

• As study participants? (No)
• Involved in undertaking the research in some way or ways
• Levels of involvement – a continuum
• Consultation – Collaboration – User-led or controlled
• Context specific – type/level of involvement may/can vary
Why involve service users in research?

• Ask different questions – change the research agenda

• Ground research in the experiences and priorities of service users

• Use different methods e.g. participatory research, focus groups, user interviewers

• Develop different instruments – user-valued/patient-reported outcome measures

• Shed new light on old questions

• Aid recruitment, dissemination & implementation

• Required by funders

• Morally right – public-funded research of public services

• Hidden talents amongst ‘service users’

• Capacity building/empowerment in service user organisations/citizens/society

• Fun!
How might people be involved?

- Consultation – Collaboration – User-led or controlled
- Steering/Advisory group member(s)
- Initial ideas for research
- Consult/collaborate on design
- Instrument development and testing
- Designing & testing patient information leaflets
- Advising on ethics applications
- Promoting studies/recruiting participants
- Employed as researchers – conducting interviews, focus groups, questionnaires etc
- Analysis – qualitative & quantitative
- Interpreting results
- Contributing to reports and papers
- Presentations to conferences, patient groups, staff etc
- Feeding into new research topics
Examples from our research

**City128 study of observation and self-harm**
- Advisory group, instrument design and testing, interpretation, papers

**Tompkins acute ward study**
- Advisory group, interviews, analysis, papers

**Peer Support Pilot RCT**
- Advisory group, RA and PSC and PSW recruitment, PSWS, training design, recruitment leaflets, Framework analysis

**Peer Support Cluster RCT (proposed)**
- Project team, advisory group, project manager, researchers (interviews)

**COCAPP: Care planning, recovery and personalisation**
- Project team, ‘lived experience’ advisory group, project advisory group, researchers (interviews)

**Service User Group Advising on Research (SUGAR)**
- How it works
- Advantages of a group...
Service User Group Advising on Research (SUGAR)
Examples of user-led research

- Diana Rose et al (2003, 2005) conducted study of Electro-convulsive Therapy (ECT)
- Systematic review from a patient perspective, reviewing and critiquing the evidence in published papers
- Two key researchers had personal experience of ECT
- Study focus, design and execution all user-led
- Results published in BMJ and British Journal of Psychiatry and influenced NICE guidelines on ECT

- A model for developing outcome measures from the perspectives of mental health service users.
- Diana Rose et al (2011)
- Describes a methodology for developing outcome measures for use in large studies entirely from the perspective of mental health service users.
- Mixed methods model starting with a participatory and qualitative methodology and proceeding to psychometric testing.
- At all stages, the researchers are themselves mental health service users.
Challenges and barriers

- Resistance & anxiety amongst researchers
- Lack of participatory skills amongst researchers
- Time-consuming (e.g. recruiting suitable people, involving in discussions)
- Costs & Funding (especially in development stage)
- ‘Representativeness’ (?) & identifying/recruiting suitable people
- Training and support
- Time-consuming (e.g. whole process can take longer esp analysis)
- Challenges to your views and thinking!
- Tensions between researchers (including user researchers)
- Illness and relapse
- Child care, dependent care, travel difficulties
- Issues of ‘ownership’ and ‘authorship’
Tips for success

- Commit time and resources
- Plan and anticipate
- Take it seriously not as an afterthought
- Role descriptions
- Clarity about roles, responsibilities, expectations
- Be honest about everything including limitations
- Provide training, development & support
- Be real – human – approachable
- Be flexible
- Pay people whenever possible – and on time
- Provide food and drink when possible
- Socialise
- Say thank you many times
- Ask what is working and what needs to change – and change it
Lessons learned for hard times

• Working alongside service users is enormously rewarding and improves your research and ideas

• Can be time and energy-demanding but worth it

• Funders now demand and reward user involvement
  • projects rejected for lack of user involvement
  • strong positive reviews for good user involvement

• Seek and build teams and groups - both of service users/carers and academic colleagues – unity is strength
Resources

  • *** Excellent overview; good references

• INVOLVE http://www.invo.org.uk/index.asp
  • A national advisory group, funded by the National Institute for Health Research (NIHR).
  • To support and promote active public involvement in NHS, public health and social care research
  • ***Excellent resources; order or download for free

  • ***Useful collation of evidence and case studies demonstrating impact.
More resources

• Brief Guide to Involving Mental Health Service Users in Research
  UK Mental Health Research Network

• Good practice guidance for involving carers, family members and close friends
  of service users in research.
  Julie Repper, Alan Simpson & Gill Grimshaw (2011) NIHR Mental Health
  Research Network.
  • http://www.mhrn.info/data/files/MHRN_PUBLICATIONS/REPORTS/Carer_good _practice_guidance_-_complete.pdf

• User involvement in research for nurses. RCN Guidance.
  Tracy Williamson et al (2007) RCN.
Books


References


Thank you

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