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

- Frankham, J. (2009) Partnership Research: A review of approaches and challenges in conducting research in partnership with service users. ESRC, National Centre for Research Methods. http://eprints.ncrm.ac.uk/778/
- *** 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

- Staley, K. (2009) Exploring Impact: Public involvement in NHS, public health and social care research. INVOLVE, Eastleigh.
- ***Useful collation of evidence and case studies demonstrating impact.

More resources

- Brief Guide to Involving Mental Health Service Users in Research
  Louise Morgan (2006) Service User Research Group for England (SURGE)
  UK Mental Health Research Network
- *http://www.mhrn.info/data/files/FOR_RESEARCHERS/Brief_Guide_to_Involving_Mental_Health_Service_Users_in_Research_2006.pdf*

- 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.
- http://www.rcn.org.uk/__data/assets/pdf_file/0003/78744/003140.pdf

Books

- Morrow, E. Boaz, A., Brearley, S. & Ross, F. (2012) *Handbook of Service User Involvement in Nursing and Healthcare Research.* Wiley-Blackwell, Chichester.

- Sweeny, A., Beresford, P., Faulkner, A., Nettle, M. & Rose, D. (Eds) (2009) *This is Survivor Research.* PCCS Books, Ross-on-Wye.

- Wallcraft, J., Scrank, B. & Amering, M. (2009) *Handbook of Service User Involvement in Mental Health Research.* Wiley-Blackwell, Chichester.

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- Callard, F., Rose, D. & Wykes, T. (2011) Close to the bench as well as at the bedside: involving service users in all phases of translational research. Health Expectations, May 25. doi: 10.1111/j.1369-7625.2011.00681.x. [Epub ahead of print]

- Gillard, S., Simons, L., Turner, K., Lucock, M. & Edwards, C. (2012) Patient and Public Involvement in the Coproduction of Knowledge: Reflection on the Analysis of Qualitative Data in a Mental Health Study. Qualitative Health Research, 22(8), 1126-1137.

- Rose, D., Evans, J., Sweeney, A., Wykes, T. (2011) A model for developing outcome measures from the perspectives of mental health service users. *International Review of Psychiatry,* 23(1):41-6.

- Rose, D., Fleischmann, P., Wykes, T., Leese, M. & Bindman, J. (2003) Patients' perspectives on electroconvulsive therapy: systematic review. BMJ, 326: 1363.
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Thank you

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