This research is a partnership between Northumbria University, Northumberland, Tyne and Wear NHS Foundation Trust and Northumberland, Tyne and Wear Service User and Carer Network.

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Flash Card 1:

Setting up the Research Project

For more information visit: http://www.rwire.co.uk/

Setting up the Research Project:

- ✓ Find out who knows about the kinds of things that are important to research in the area?
- ✓ Contact groups/organisations/individuals and form links with people who are already engaged in this area and/or type of research.
- ✓ Work with them to develop a research question and methodology.
- ✓ Finance - how is researcher travel and time going to be financed at this set up stage?
- ✓ Look carefully into who might fund your research.
- ✓ Keep a tight focus on clear achievable aims within the research.
- ✓ Having got funding, look early to organising honorary contracts, DBS and health checks - time and support will be needed to set them up.
- ✓ Work closely with NHS Trust staff to establish what is required from the Trust e.g. Research and Development Department.

Additional resources:-
- **NHS Research and Development Forum http://www.rdforum.nhs.uk/content/**
- **Local Research Design Services http://www.rds-sc.nihr.ac.uk/**
- **National Institute for Health Research http://www.nihr.ac.uk/research/**

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Flash Card 2:

Sustaining the Research Project

For more information visit: http://www.rwire.co.uk/

Sustaining the Research Project:

Keeping people engaged:

- ✓ Focus on researching an area of interest to the people involved. Learning being applied to real issues in people's lives, not just academic or professionals ideas.
- ✓ Valuing and recognising peoples input and skill sets in the project in terms of financial and non financial benefits (e.g. conferences, library access, work based skills, being part of the academic community) is important.
- ✓ Mutual support, listening, discussing and responding to group suggestions is vital.
- ✓ Be mindful of people's personal and organisational agendas and how these can be balanced against the purposes and values of the project. These agendas can of course change over time.
- ✓ Researchers will learn, develop and may shift their identities during the project, this has implications for everyone.
- ✓ Providing flexibility for researchers to step on and off of the work is important.
- ✓ Supporting the inclusion of researchers at all stages of the research process will challenge the boundaries of organisations and systems.
- ✓ Ensure that all the roles are clear – jointly develop a research job description.

Additional resources:
See researcher job description on the RWIRE website.

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Flash Card 3:

Co Production

For more information visit: http://www.rwire.co.uk/

Co Production:

- ✓ Ultimately this work concerns blurring the boundaries between service users, carers, academics and professionals.
- ✓ At all stages of the research process, work is produced together.
- ✓ It involves paying attention to both the process of doing the research and the outcomes of the research.
- ✓ Requires a serious time commitment.
- ✓ Involves a commitment including personal research support, project progress and updates, meeting management and cross group communication.
- ✓ Belief in the abilities of individuals and the group as a whole.
- ✓ Valuing and respect for everyone's experience, knowledge and skill.
- ✓ Developing a place for shared understanding – have regular informal/formal meetings.
- ✓ Do not assume people will or will not wish to be involved at any point.

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Flash Card 4:

Research Ethics

For more information visit: http://www.rwire.co.uk/

Research Ethics:

✓ Ethics is the systematic study of applied morality.

✓ The NHS Research Ethics Committee is concerned with protecting 'research subjects' from harm and ensure nothing happens to these subjects without valid consent.

✓ Informed consent is not a 'one off' event but an ongoing negotiation.

✓ Provide straight forward, clear information to participants.

✓ When considering safety and risk look to both participants and researchers.

✓ Problems exist in conceptualising mental health service users and carers as 'vulnerable' subjects in research. This in itself can be disempowering.

✓ The cultural contrast between risk averse, hierarchical, tightly structured ethical protocols and the continuously evolving, loosely structured, power sharing nature of emancipatory research is a tricky one.

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Flash Card 5:

Research Training:

For more information visit: http://www.rwire.co.uk/

Research Training:

✓ Have a basic course framework, but be flexible in developing content in response to the needs of the learners.

✓ Be mindful of people entering education for the first time or having had previous negative experiences of education.

✓ People may need to share personal experiences in a safe and valued way.

✓ Do not underestimate the importance of social time around coffee and lunch breaks in helping form a research team.

✓ Be innovative in evaluating student learning and assessment processes, don't just go with a traditional written assignment.

✓ Breaking down barriers between mental health service users, carers and the university is a three way learning process.

✓ Consider any changing identities – service users and carers moving through being students to researchers.

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Flash Card 6:

Analysis of Findings

For more information visit: http://www.rwire.co.uk/

Analysis of Findings:

✓ Creating the opportunity for service users and carers to be involved in data analysis challenges perceptions of traditional roles and boundaries.

Why involve?

✓ Service users and carers add value to data analysis because they have lived experience.
✓ There is the assumption of a common experience, but strength lies in multiple perspectives.
✓ Discussing the data together and contesting perspectives leads to a shared understanding of what is important.

What we did?

✓ Work together to create a pre-coding structure that is responsive to new and emerging themes.
✓ Go at the pace of the researchers, but keep in mind the timescale of the project.
✓ Introduce one or two research methodology articles to put the work into context.
✓ Talk together about the impact of reading different research participant stories.

Additional resources:

Sweeney, A., Greenwood, K. E., Williams, S., Wykes, T., & Rose, D. S. (2013) 'Hearing the voices of service user researchers in collaborative qualitative data analysis: the case for multiple coding', *Health Expectations,* 16(4), pp.89–99.

Cho, J. and Trent, A. (2006) 'Validity in qualitative research revisited', *Qualitative Research*, 6(3), pp.319–340.

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Flash Card 7:

Key Recovery Themes

For more information visit: http://www.rwire.co.uk/

Key Recovery Quotes:

✓ *'Recovery is a process owned by the individual. Each individual is at different stages of recovery and just cos you've suffered a blip doesn't mean you have to start from stage 1 again. You simply get on at the right place for you. Recovery is owned by you, not by anyone else.'* (Service User)

✓ *'I had a WRAP plan. A wellness, recovery action plan. Which highlights my triggers, early warning signs. It tells you what steps I need to take to hopefully prevent things breaking down. It has a crisis plan section. And I would hope that that would be used. And that I would use that in planning for my future care.'* (Service User)

✓ *'A person can be helped in their recovery journey by people who help them to believe in themselves and their own future, by building on their strengths, working towards their goals, experiencing and celebrating successes, learning to manage their own challenges in many different ways and learning when they would find support helpful...'* (Service User)

✓ *'set backs are part of the recovery process and also that recovery doesn't mean cured it means living with your illness in the best way you can for you.'* (Service User)

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Flash Card 8:

Key Care Coordination Quotes

For more information visit: http://www.rwire.co.uk/

Key Care Coordination Quotes:

✓ *'involves establishing a trusting reliable relationship with the user of mental health services'.* (Professional)

✓ *'care coordination for me is having a team of people who work with me to help me deal with my mental health issues. This is an equal partnership with a shared goal and vision'.* (Service User)

✓ *'its lip service, box ticking'.* (Carer)

✓ *'... care coordination is not for care and treatment of the patient. Care coordination is the administrative process that is used to capture the care and treatment to patients'.* (Professional)

✓ *'I've always been listened to and I felt they've worked with me, they've valued what... my opinions are, I've not been pushed into anything. I've not been treated as someone who hasn't got anything to give in my recovery or anything like that.'* (Service User)

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Flash Card 9:

Good Practice in Care Coordination

For more information visit: http://www.rwire.co.uk/

Good Practice in Care Coordination:

✓ Focus on listening not form filling.

✓ The need to appreciate different perceptions of recovery.

✓ Take a recovery focus from the very start of care coordination.

✓ Its important to include and educate family and supporters and in turn be educated by them.

✓ Know the boundaries of confidentiality.

✓ Recognise when service users, carers or professionals are 'getting stuck' in services.

✓ Opportunities for taking responsibility and positive risk are key.

✓ Signposting to information and peer support is vital.