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**Involvement in research: tensions and insights for  
a service user and social work researcher.**

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# The Journey

- Being a service user
  - ‘experiences of disempowerment and disability, and loss of identity’

My journey as a service user experiencing first mental health symptoms

## Small steps to recovery

- Wanting to give back
- Wanting to change things for other service users
- Thinking that a better way is possible
- Becoming someone else through my experiences?

# What is user led research?

“This changed approach to research and knowledge formation needs to start with the full and equal inclusion of the experiences and knowledges of service users in research. For this to be possible on truly equal terms, requires the full and early involvement of users and their organisations in the construction and process of research and evaluation, as indeed of other areas of social care....”. Beresford (2001, p. 350)

# Involvement of service users and carers in research

- PhD study ‘Exploring the meaning of recovery to carers of people with schizophrenia’
- Involvement of a carer and a service user in steering group to develop research process and tools
- Carer co-presented the training programme
- Research participants involved in the developmental cycle of reviewing the training programme. (Fox, Ramon and Morant, *forthcoming*)

# Involvement in psychosis workshops (CPFT)

- Involved in peer led training / discussion groups to encourage awareness of psychosis and its experience with non-clinical research staff
- Underpinning the development of research programmes
- Training people who undertake research but are not trained in mental health

# Different kinds of wisdom

- Expertise by experience
  - Teachers in the process
- Academic wisdom
  - What the non-clinical researchers bring to the table
- Practice wisdom
  - Learning to connect expertise by experience with academic wisdom.

# How do you balance personal and professional identity?

- Recovery is a personal process (Slade, 2009).
- The self impacts on the research (Beresford, 2001).
- How do you protect the self?
- Resilience versus pain.
- Learning versus preservation of experience.

# Involvement in professional training

- Social work (DH, 2002; Levin, 2004)
  - Mandated input into training
  - Anglia Ruskin University - Service user / carer involvement group
    - [www.anglia.ac.uk/suci](http://www.anglia.ac.uk/suci)
- Nursing education
  - Nursing – The Francis Report



# Strengths

- The learning builds on different kinds of knowledge generated from expertise-by-experience, practice and academic research (Uhm et al, 2012).
- It recognises the value of service user experience (Ramon, 2003)
- It includes their perspective in the co-construction of knowledge (Fox, 2015)

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