Nothing about us without us?

User / survivor involvement and leadership from research to clinical practice.

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Definitions

**Service user / survivor:** terms used to describe people with **lived experience of mental health problems and/or services**. May be a “survivor” of one’s own difficulties or the psychiatric system (or both).

**Involvement:** wide spectrum of practices **to include those impacted by research &/or clinical practice in its development**, but not typically handing over control.

**Co-production:** producing research and/or services with those impacted by them, theoretically on an **equal basis**.

**Survivor research / User-led research:** research explicitly informed by lived experience, **led by service users / survivors**. Historically closely aligned with the service users & psychiatric survivor movement(s) and **emancipatory research**.

**Mad studies:** emerging field of concerned with & typically carried out by those with **lived experience of “madness”** (e.g. voice-hearing, suicidality, self-harm)

**Further reading:** Sweeney et al (2009), *This is Survivor Research*  
Spandler, Anderson & Sapey (2015), *Madness, distress and the politics of disablement* - especially Peter Beresford’s chapter *Distress and disability: not you, not me, but us?*
Where do we fit in the research cycle?

- Involvement at “undertaking” “disseminating” & “implementing” stages relatively common.
- Less common in earlier stages - especially identifying & prioritising areas of study.
- Survivor researchers might not have same priorities as other areas.

NIHR’s research cycle
Where do we fit in the research cycle?

- User/survivor research priorities may be directly related to clinical practice and/or social policy - or might be about developing our own self-understanding.
- Survivors’ priorities for clinical research may not be the same as clinicians’!
- We may or may not “pass as sane.”

National Survivor User Network’s 4Pi standards

- **Clarity & transparency** are key principles.

- “The purpose of involvement needs to be both clear and shared with all of the people who are likely to be affected... The potential for change and the limits of change need to be made clear.” (P.8)

- Don’t expect us to represent everyone like us! There are a multiplicity of voices and views among user/survivors - aim to reflect this diversity.

- Feed back on the impact of involvement - make it clear what’s changed as a result of our work, even if it’s small.

There are user / survivor produced resources out there to support individuals and organisations with involvement.
Council consultation on day centre changes, studied by Healthwatch Camden

An example of both excellent (Healthwatch) and terrible (Council / NHS Trust) involvement practice

“An abusive relationship is when someone tells you they care for you while hurting you. This is how the Trust and Council dealt with us.”

• Tokenistic involvement can recreate abusive dynamics if an organisation in a caring role says they are helping or “empowering” you while in fact hurting you. This risks retraumatising.

• Can be avoided by clarity about how much power is actually given to service users. Take seriously the responsibility of offering to listen to people who may have lived many years in silencing systems.

• Research that truly bears witness to people’s pain is powerful. There are no neutral decisions when you are researching people’s lives.

Full Healthwatch report here.
The research-practice and research-experience gaps: women & physical restraint

“It feels a lot like rape.”
(Service user describing restraint)

- **Agenda study** (2015): more women than men restrained face-down; more girls restrained than boys; huge regional variation.
- Some progress on this: Seni’s Law.
- But policy “solutions” sometimes introduce more coercive measures - e.g. staff-controlled body cams to monitor patients’ behaviour - although regional variation & research on aggression point to importance of staff behaviour & ward culture in reducing restraint & its precursors.
- Often exclude restraint in non-mental health specific settings (e.g. A&E) from both research & policy – dividing related experience into separate domains.
Austerity, trauma & the welfare system

“Being on benefits is like being in an abusive relationship with the state. The rules of engagement are complex and ever changing, the penalty for getting it wrong: brutal.”

Ria Dylan, “The life and times of a modern day mental”, in *Asylum 25.3*: special feature on welfare rights edited by Danny Taggart and Ria Dylan
Further resources / references

National Survivor User Network

4Pi standards: support with implementation

WISH - national user/survivor led women’s mental health organisation

Universal Credit and domestic abuse: parliamentary report; comment from CEO of Solace Women’s Aid (August 2018)

The Child Tax Credits rape clause & coercive control

My artwork & related presentations are also available online.