

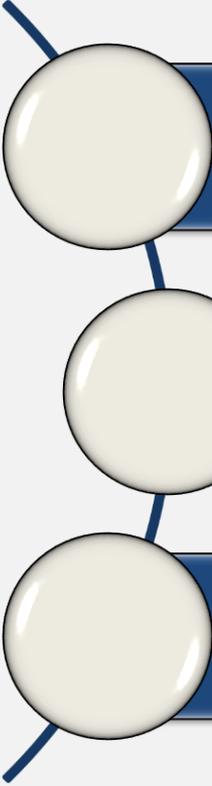


Involving Service Users in Mental Health Research

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Overview



Why engage Service Users in the research process?

What do we mean by engagement?

How do we produce inclusive, accountable research?



**Why involve Service Users in
the research process?**

Benefits to Service User

- Those from socio-economically deprived and minority ethnic groups are less likely to engage than the wider public – proactive engagement increases their involvement and representation
- Build capacity in both the state and the public through sharing of expertise, experience and information (Barnes et al, 2007)
- Empowerment and sense of control, self-efficacy and destigmatization (Sweeny, 2015).

Interventions co-designed by service users:

- Have higher rates of efficacy
- Have increased uptake
- Are more trusted by their beneficiaries

(Moore et al, 2015; Unger and Liebenburg, 2014; Unger et al, 2012; Koch et al, 2005)

Benefits to the Researcher

- Increased trust in the institution doing the engagement and builds community allies/advocates (Bishop and Davis, 2002)
- Increased fairness in outcomes (Tompkins et al, 2004)
- Increased enjoyment and satisfaction, positive changes to own perspective and opportunities for career progression (Pollard and Evans, 2015)
- Improved access to harder to reach populations

Taking off the rosy glasses

It's not as easy as it looks

- Time consuming, labour intensive and often costly (Pollard and Evans, 2015)
- What do you do if user perspectives clashes with researcher perspectives?
- Those most willing to engage can often be those with the most extreme perspectives, a bone to pick, etc
- Bad experience likely to hamper future attempts at engagement (Arnstein, 1969; Bishop and Davies, 2002, Kendall; 2003)



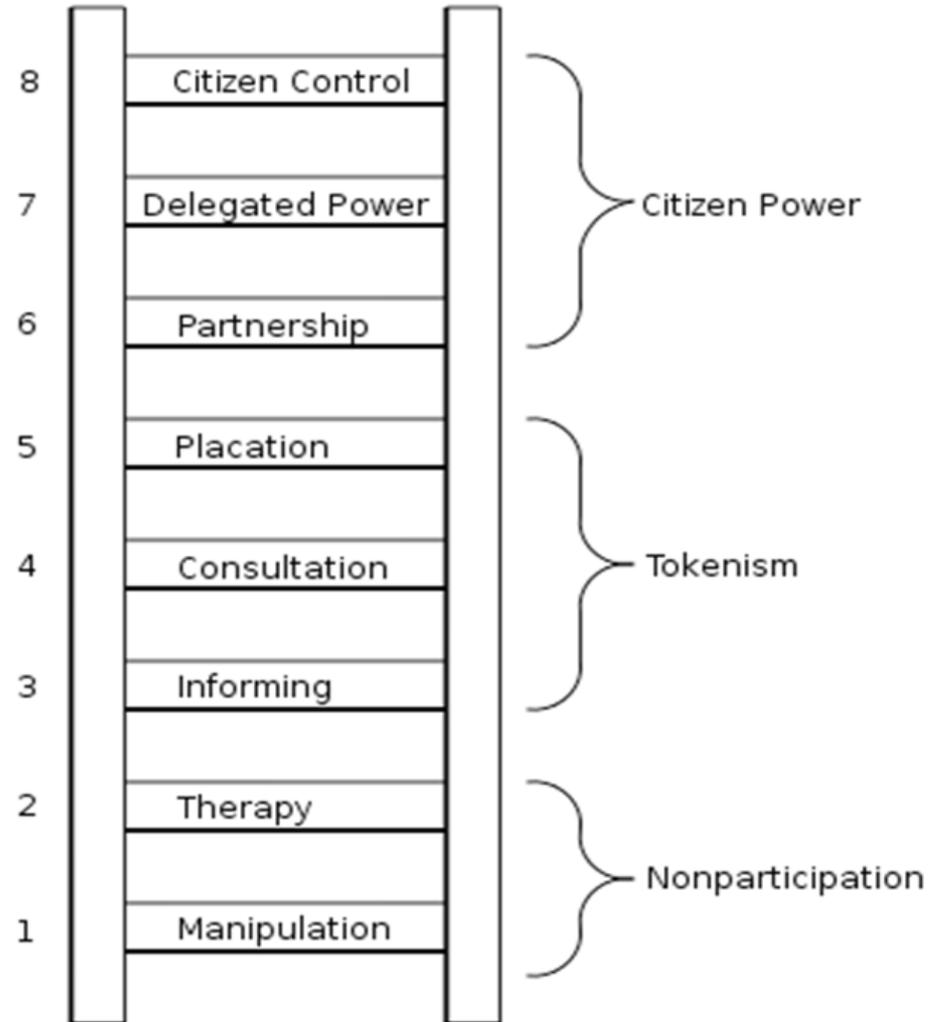
What is Engagement and Inclusion in Research?

What is inclusion in mental health research?

- Participation has no concrete definition.
- The methodology and approaches to participation can differ, and the context of power relationships and cultural norms impact process and approach
- Participant observation, ethnography and immersive research (e.g., Goffman and asylums)
- Emergence of lay perspectives and first hand accounts
- Turner (2001) and 'Experts by experience'

Arenstein's Ladder

Is it meaningful participation?



Resistance to Inclusion

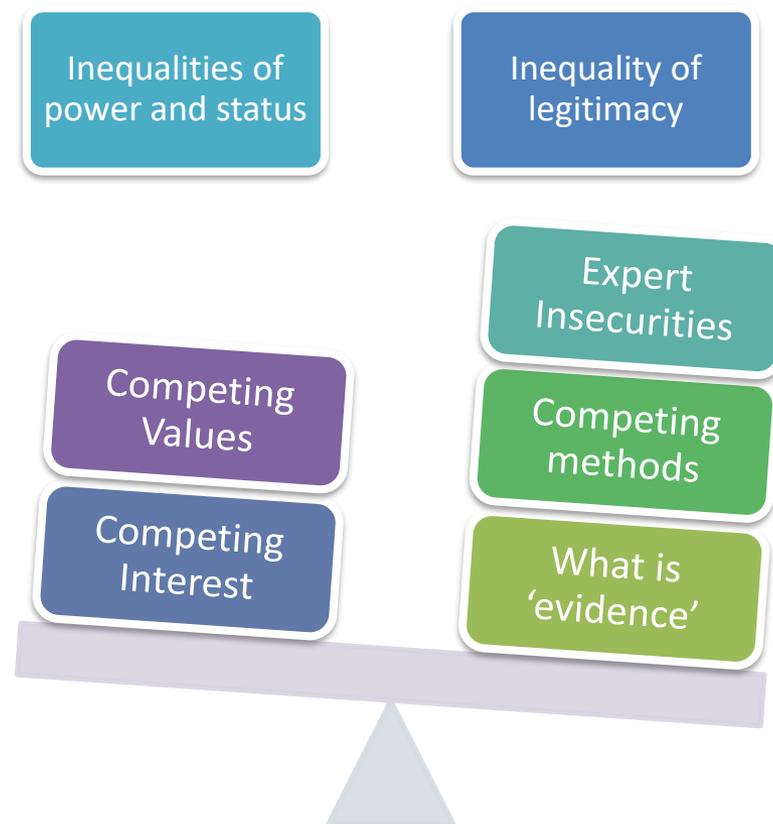
How service users are 'silenced'

- Perspectives disregarded when they don't match the expert
- Participants deemed irrational
- Contributions treated as 'opinions' or 'anecdotes'
- Perspectives are reframed to match professional views (Pilgrim and Rogers, 1999)

DO WE LAUD PPI PUBLICLY BUT DISMISS IT IN PRACTICE?

Power and Conflict

Sources of imbalance in PPI

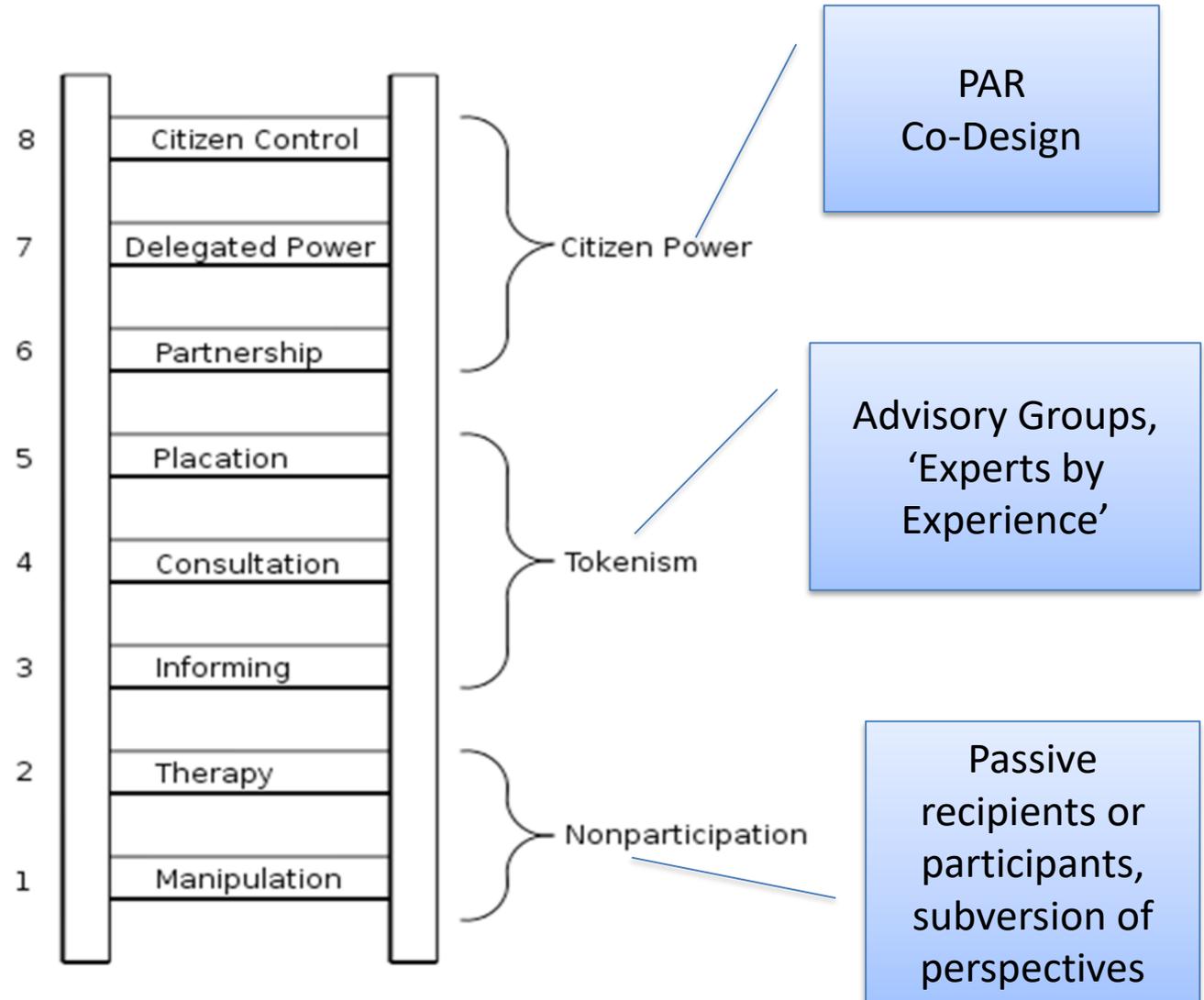




How do we do it?

Coming back to the ladder

How much are you willing to give?



Guidance on Engagement

Learning from Best Practice

- NIHR development of INVOLVE guidance , examples of best practice and step by step guidance

<http://www.invo.org.uk/>

- Significant investment in projects examining the impact of PPI across healthcare research, several of which involve mental health users

Participatory Action Research

- Moving from ‘fishbowl’ research
- Brings participants in as full partners in the research
- From inception to completion and dissemination
- Co-design, affected groups as participants *and* partners in research

Difficult in positivist approaches and where complex statistical analysis required, BUT – creative approaches can get around some of the limitations of co-design

Experts by Experience

Advisory Bodies

- How will you classify representation?
- Hierarchy of the group(s)
- What role with they play, at what point?
- What will you do if there is a challenge to the findings?
- How much control are you willing to relinquish?
- How are group members selected – are you cherry-picking experts?
- Keep in mind your power: you control the language, systems and norms of participation

Capacity, Consent and Participation

- How is engagement and inclusion achieved where capacity and informed consent are questionable?
- How far can proxy or carer representation go? – issues of centring on carers in dementia research
- Balancing inclusion, ethics and participant safety

Examples from the NIVHWS

Incorporating a hidden population

- Staged work packages, interconnected and informing research design
- Participant validation from design to dissemination
- Keynote listeners
- Recognition of power dynamics in representation (is the representative group representative?)



Thank you

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