Participatory research and user-led research: novelties and dilemmas

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Positioning myself and my research

- Service user all my adult life
- Academic jobs 1972-1986 – sociolinguistics, social sciences, women's studies
- Hid service user status until became impossible – medically retired 1986
- 10 years 'living in the community'
- 1996 two identities came together to do user-led research

But something else happened 1986-1996

- Fledgling user movements across Europe and North America 1970s
- 1986 went to meeting of local user group – forced to frame madness and responses differently
- Start of long journey – life-changing

An example from 1988

- Activist local group at time of asylum closures in England and USA
- Mainstream research in both countries concerned with enumerating possible negative consequences of deinstitutionalisation – violence, murder, homelessness, imprisonment
- RCT in England, McArthur work in USA
- We did something different and was grounded in experience

Colney Hatch Lunatic Asylum (est 1851)

Friern Hospital corridor 1974 – I walked the line

What did we do?

- Interviewed people about their experiences of the asylum compared to new services – DGHs and Community Mental Health Centres
- Results not simple – there were things respondents missed as well as things they liked about the move
- Point – we asked people about their experiences, in the context of fundamental policy change, people who generally thought could not speak for themselves

Reaction

- Methodologically, this was not rigorous research but made a splash
- Report discussed at Maudsley Hospital where RCT was being conducted – a bit baffled I am told
- Platform with Leonard Stein – ACT – quantitative evaluation
- But this is the tradition, the new narrative, social experience is not structured like a regression equation, but how to elicit and analyse – it's still research

Changing the Research Relationship

- May not think that research involves a ‘power dynamic’
- Participatory research – recognises that dynamic and tries to level it
- Mostly the researcher is not part of the community but works with them at all stages of the research process
- Novelty is that we share some of the same experiences as our participants
- Not without difficulties – slowly recognised through both theorisation and experience

Can Outcome measures really be an example of participatory research?

Service user generated PROMs

- Patient Reported Outcome Measures a hot topic at the moment in both UK and USA
- To be used clinically and in research
- But may be devised purely by clinicians and conventional researchers – patients just fill them out
- PG-PROMs are entirely user-generated
- Researchers are also service users – "insider knowledge"

So the example is about outcome measures

- May seem odd as an example of participatory research
- But in context of this turns method of developing outcome measures on it's head
- Usually top-down but our method starts with people's experience of what's being evaluated
- Changes also in that researchers themselves share that experience

Method

- Participatory research
- Attempts to reduce the power relations between researcher and researched
- In user-led research, researchers have the same experiences as the participants
- All are mental health service users – this is what makes the research user-led
- A new development even within participatory research

Example – in-patient care (VOICE)

- Much anecdotal evidence and evidence in the 'grey' literature that profoundly disliked
- My experience too
- Wanted to do something more rigorous
- Main outcome in an RCT
- Collaborative but out part was user-*led*

Views Of Inpatient CareE: VOICE Participants

- People who had been in-patients in the local Trust within the previous two years
- One group specifically made of participants who had been involuntary

Focus groups

- 6-8 people: 4 groups
- One facilitator with experience of in-patient care and other also a service user
- Meet twice to make sure we have accurately captured their views
- Thematic analysis using qualitative software after both 1st and 2nd wave

Drafting the measure

- Done by the researchers on the basis of the qualitative analysis
- Quantitative and qualitative questions
- Researchers also use own experience
- Items bottom-up rather than from the literature and existing questionnaires

Expert Panels

- One drawn from focus group members and one independent
- Also been inpatients in previous two years
- Close to the concept of ‘experts by experience’
- Tasked with amending and refining the measure and making sure that language and layout are appropriate
- Usually quite a few changes made at this stage

Feasibility study

- Final stage of constructing measure
- ~50 people complete the measure and we find out which parts are easy to complete and which not
- Iterative process
- In this project the participants were actually in hospital

Psychometrics – mixed methods

- Mixed methods research
- We do this because it is appropriate but also to show that user-led research can be rigorous
- One mainstream researcher said users could never produce measures because they would never understand psychometrics

Test-retest reliability

- ~ 50 people complete the measure twice, one week interval between
- Standard textbooks say ‘subjects’ have to be ‘cognitively intact’
- Our participants mostly experience of psychosis but perfectly able to do this
- Because the measure user-generated?
- Better test-retest reliability than most measures

Main question clusters

- Security
- Staff / patient interaction
- Ethnicity
- Coercion

But there are dilemmas

Reflections 1 – Power

- Can try to reduce power relations but never can
- More difficult on acute wards
- Held our focus groups etc in community venues and provided food and drink
- Paid ‘decent’ amount within benefits regulations
- One participant “I forgot you are not a psychiatrist”
- Another – “tell us your experience now”
- One thing to say at start you have been in hospital, another to go into detail, should I have done – principle of reciprocity

Reflections 2 – gatekeepers

- Participatory researchers in low resource settings – community has hierarchies, you only reach those the gatekeepers allow eg gender
- Defeats whole object
- Our 'gatekeepers' community mental health professionals
- Had good mix in terms of gender, age, ethnicity, sexuality
- But who did we miss – those deemed to 'lack capacity', 'too unwell', also maybe 'illegal' migrants
- Needed those people as experiences of acute care different and most powerless

Reflections 3 – the power of 'race'

- Researchers two white, straight women
- Most participants of African or African Caribbean heritage
- Did this make a difference?
- Demographically 'representative'
- But metrics not equal to perspectives and possible certain issues could not be voiced

Reflections 4 – feedback

- Dragon Café – user-led space, arts-based but also other things, very valued locally
- Took VOICE there to get their feedback
- “I could never have filled that in when I was unwell”
- BUT another said she could tell it had been designed for service users as so simple “an insult to our intelligence”
- And we always go on about how these measures are “easy for service users to complete”!

Ethical Dilemma

- Abusive practice repeatedly associated within one ward
- Should we break confidentiality
- Not without agreement of participants
- Suggested to them and all agreed
- Took to CEO whom we knew well
- Preserved anonymity and implemented
- BUT We are not an advocacy organisation…….

Changing the method

- Two most recent measures
  - Recovery from addiction
  - Side-effects of medication
- Both of these introduced perspective of professionals
- Delphi study BEFORE focus groups with service users
- Frames the study and papers as well
- Coproduction or dilution of method?

Some more context

Why 'User-Led Research'?

- For a long time in England and elsewhere it was 'user **involvement** in research'
- Many good things happened under this remit
- Remember too considerable financial and other resources were made available for this
- Other countries envied our main health research funder commitment (NIHR)

What did ‘involvement’ enable?

- Democratisation of the academy – people entered these hallowed spaces who had flunked out of school with no qualifications
- Inflecting data collection – not so much analysis
- Recently setting research priorities – challenging
- Not to say all that was happening – other things going on outside academic spaces
- And no sustainability built in

What was the status of methodological changes?

- To demonstrate that user involvement in research could be rigorous and meticulous
- To 'add' to the conventional evidence base
- To introduce a new 'piece of the jigsaw'
- Sometimes to 'challenge'
- Make research more 'relevant'
- But implicit assumption not to change the fundamentals and that's a constant tension.
- A continuum or a break?

So what can go wrong – example

- RCT of Joint Crisis Plans for
  - People who self-harm
  - People with Borderline Personality Disorder
- The language – 'manipulative', 'complex', 'demanding', 'difficult', 'sexualised'
- Very, very difficult
  - Some accepted my critiques
  - Some carried on including with regard to a student!

What are the limitations?

- Don't escape the diagnostic but also the slang of medical categories
- Realisation that method is the royal road to truth for mainstream psychiatric research
- We were not just changing the method, but trying (and failing) to legitimate a different form of knowledge
- This is about power and the power instantiated in the privileging of empirical method over theory
- Power held less by individuals than the epistemic system they inhabit which makes the privileging of method seem 'obvious'
- Epistemic injustice – we are not credible knowers
- Not good at opening this up to marginalised identities

Everybody wants stories but only certain stories will do

- Celebrity stories – how I was saved by psychiatry (strange ally in Prince Harry)
- Was asked to write my 'story of resilience'
  - I'm not – but reversal of previous assumptions
    - Can't be credible academic if a service user
    - Now you are a credible academic you must be resilient / recovered
  - The people who are those marginalised and on the benefit circus that characterises austerity in the UK
  - Social justice, peer support and a wicked sense of humour
- My story politely declined

A long, roundabout way of saying

- I do much less PPI (Patient and Public **Involvement)** in research
- Most of it now done in England by an NGO that is not user-led
- Some SURE members continue but introducing sociological and cultural studies thinking
- Changing knowledge to give credibility to those previously positioned as 'unreason' requires a different approach
- Stories yes but in own terms, oral history, respect the narrative however challenging
- Research not the only way of creating knowledge and academic spaces should be recognised as contingently privileged


Gracias
Thanks!
THANK
YOU!