



Participatory research and user-led research: novelties and dilemmas

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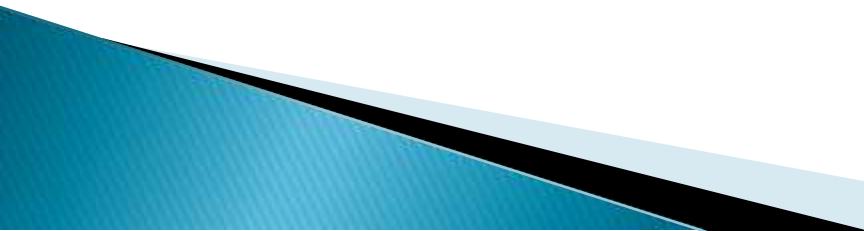
Positioning myself and my research

- ▶ 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
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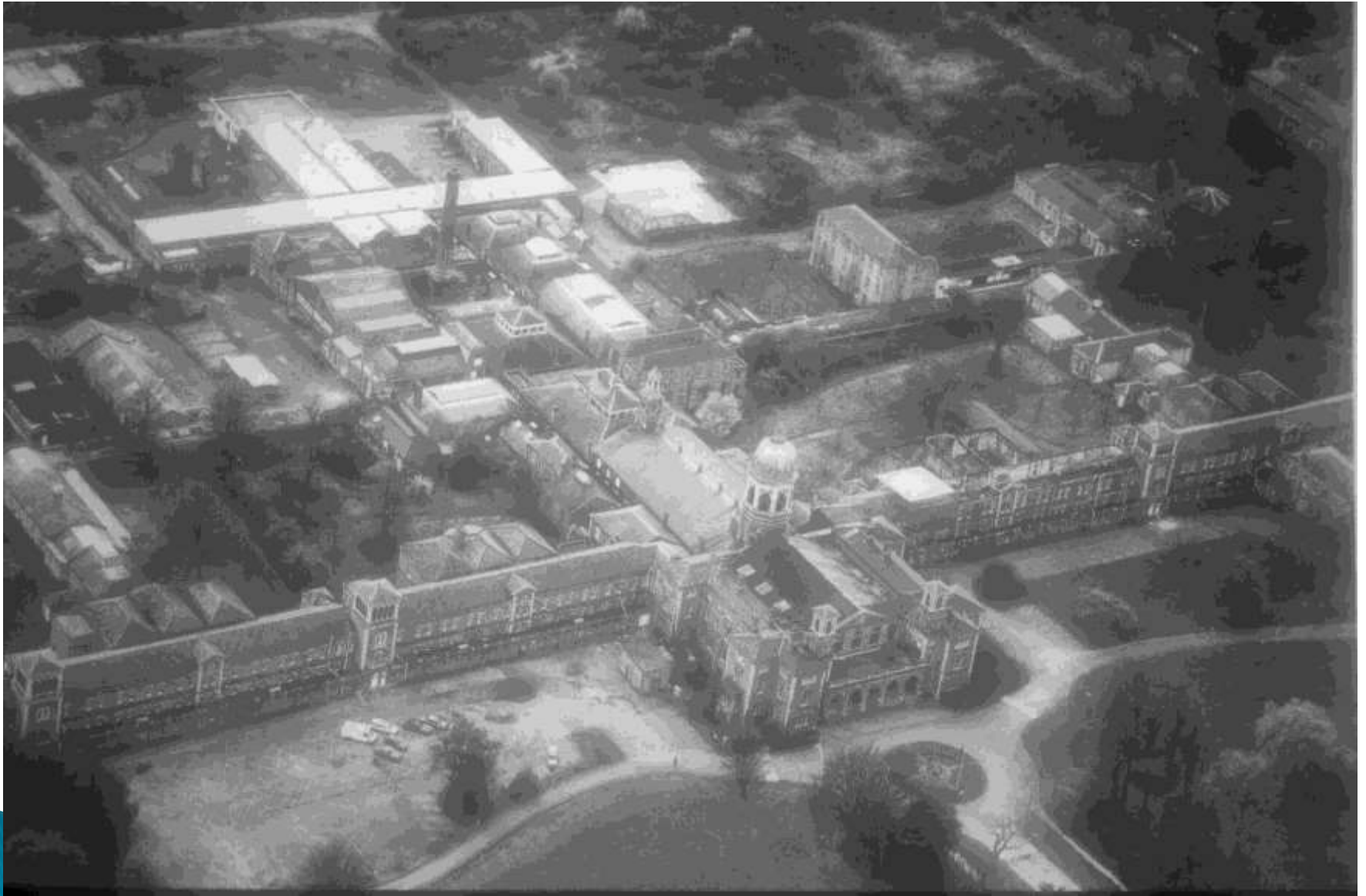
But something else happened 1986–1996

- ▶ 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
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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
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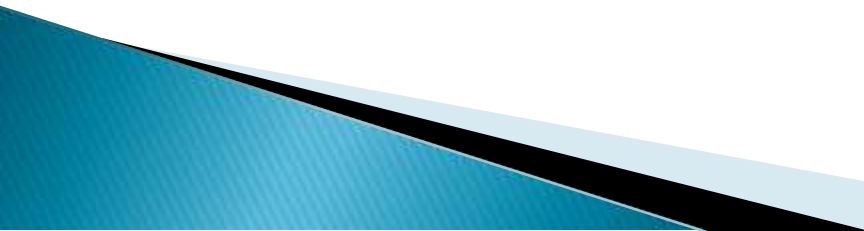
Colney Hatch Lunatic Asylum (est 1851)



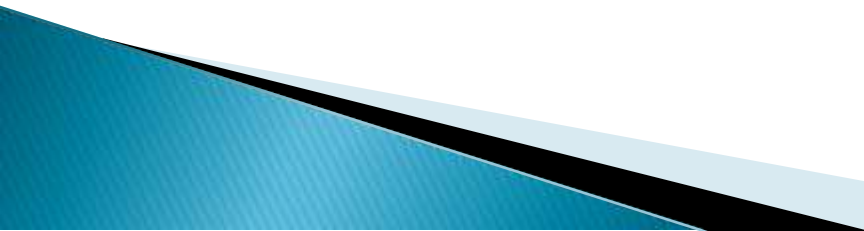
Friern Hospital corridor 1974 - I walked the line




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
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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
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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
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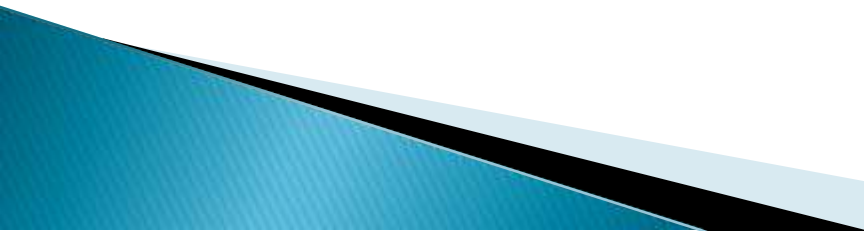
Can Outcome measures
really be an example of
participatory research?




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”
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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
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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
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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*
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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
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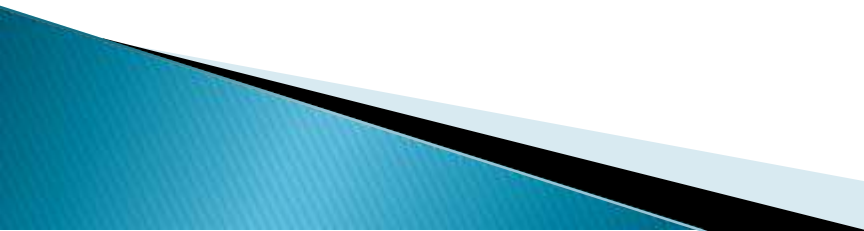
Focus groups

- ▶ 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
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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
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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
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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
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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
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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
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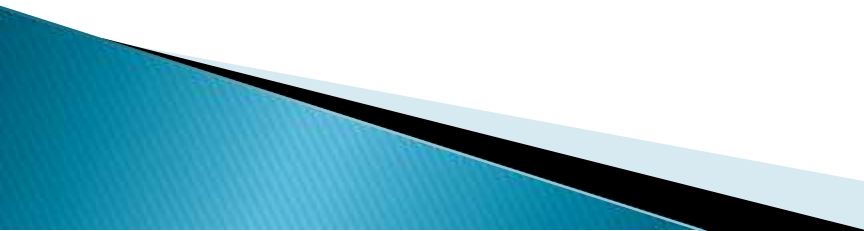
Main question clusters

- ▶ Security
 - ▶ Staff / patient interaction
 - ▶ Ethnicity
 - ▶ Coercion
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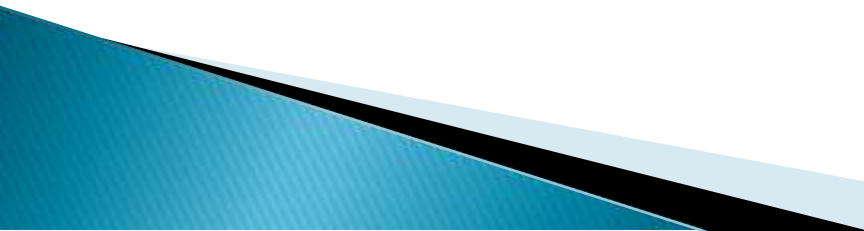
But there are dilemmas




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
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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
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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
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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”!
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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.....
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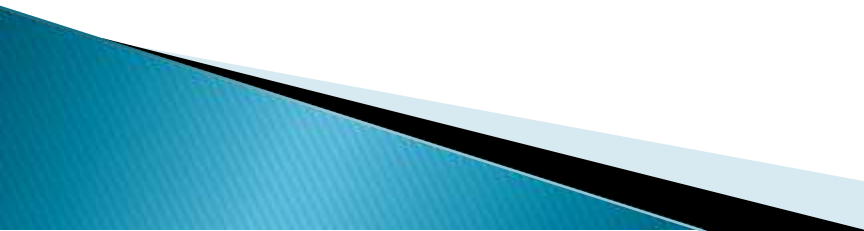
Changing the method

- ▶ 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?
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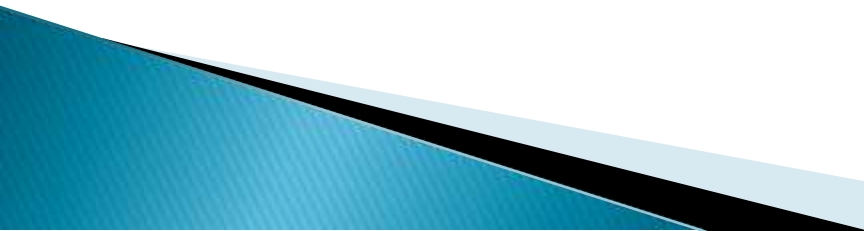
Some more context



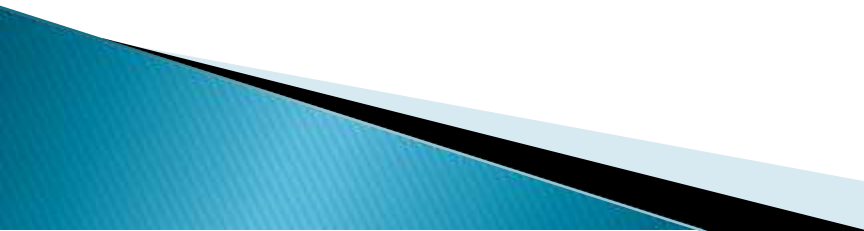
Why 'User-Led Research'?

- ▶ 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)
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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
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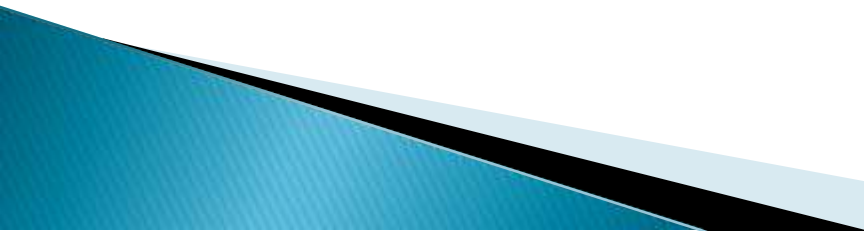
What was the status of methodological changes?

- ▶ 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?
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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
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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

