Welcome to the McPin Foundation’s methods workshop:
Integrating lived experience expertise in mental health research teams
#McPinMethods
Brian Littlechild and Karen Machin, University of Hertfordshire:

‘Going the extra mile in mental health research: Reflections on involvement at the University of Hertfordshire’
Going the extra mile in mental health research
Reflections on involvement at the University of Hertfordshire
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Addressing questions 1 and 3:

- How might models for involving people with lived experience in research evolve?

- How do mental health researchers with lived experience develop their careers and what barriers do they face?

- From the perspective of working at UH
“Every day, hundreds if not thousands of patients and the public go the extra mile to help make research happen in the UK.”

Going the extra mile: Improving the nation’s health and wellbeing through public involvement in research

NIHR, 2015
Citizen control
Delegated power
Partnership
Placation
Consultation
Informing
Therapy
Manipulation

Degree of Citizen Power
Degree of Tokenism
Non participation

Arnstein (1969)
User-controlled Collaboration

Degree of Citizen Power

Degree of Tokenism

Non participation

- Participation in decision making
- Active involvement
- Diverse range of activities
- Expertise by experience
- Collaboration with professionals
Assets: Transforming the perception of people from passive recipients to equal partners.

Capabilities: Building on what people can do and supporting them to put this to work.

Mutuality: Reciprocal relationships with mutual responsibilities and expectations.

Networks: Engaging a range of networks, inside and outside ‘services’ including peer support, to transfer knowledge.

Blur roles: Removing tightly defined boundaries between professionals and recipients to enable shared responsibility and control.

Catalysts: Shifting from ‘delivering’ services to supporting things to happen and catalysing other action.

Boyle, D., Slay, J., & Stephens, L., 2010
NEF, 2011
- Principles
- Purpose
- Presence
- Process
- Impact

Faulkner et al, 2014

‘Nothing about us without us’
How well is co-production of training and research activities actually carried out in practice?
Co-production in practice

• NHS England- Co-production is now acknowledged as key for mental health agencies

• “Services must be designed in partnership with people who have mental health problems and with carers”. (Mental Health Taskforce, 2016, p20)
Co-production in practice

• Kings Fund November 2016- http://www.bbc.co.uk/news/health-37943379- ‘plans to cut hospital services in England secret, an investigation has found’- NHS England told local managers to keep the plans "out of the public domain" and avoid requests for information, the King's Fund suggested.
Co-production in practice

Is co-production maybe something we just give lip service to?

How do we judge this?
Co-production in practice

• How can we move, in what ways, to the highest level of experts by experience co-production?
• What are the key factors in the best possible model for co-production of teaching and research?
Co-production in practice

Co-production in practice

Mental health Recovery and Social Inclusion Masters (http://raiseinrecovery.com/index.html)

“In our view, the most successful collaborations will be those where knowledge is shared in a mutual partnership between researchers, the public and health professionals.”

NIHR, 2015
INVOLVE. (2012). *Briefing notes for researchers: involving the public in NHS, public health and social care research.* Eastleigh: INVOLVE
Mental Health Taskforce (2016) Five year forward view for mental health.
NIHR. (2015). Going the Extra Mile. NIHR.
John Gibson and Humera Plappert, McPin Foundation and University of Birmingham:

‘Collaborating with people using mental health services and carers to design and deliver a research trial: Challenges and benefits from the PARTNERS2 programme’
‘Collaborating with people using mental health services and carers to design and deliver a research trial: Challenges and benefits from the PARTNERS2 programme’

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Overview

Collaborative care of severe mental illness remains a priority for the NHS including the recent NHS England 'Five Year Forward View for Mental Health' and the NICE guideline update for schizophrenia (2015) which highlights the reduced life expectancy of this population and the need for improvement in primary care healthcare monitoring: this will be an important outcome of our trial.

*We aim to help primary care and community based mental health services work more closely together.*

We think this could be achieved by developing a system of collaborative care based in GP surgeries where many adult service users are seen regularly by an experienced mental health worker (called a Care Partner) who acts as overall co-ordinator (supporting individuals to access other services and activities) and provide motivational coaching.
PARTNERS2 Aims

To better address the emotional, social and physical needs of people with stable severe mental illness in a co-ordinated way by placing a secondary care practitioner within general practice. The specialist mental health worker (who we call a ‘Care Partner’) will be guided through a detailed manual and bespoke training to work with patients and practice teams. We will also provide brief training manuals and ongoing support to practice staff.

At the end of the five year Programme, we will know if collaborative care for people with a diagnosis of schizophrenia and bipolar in England is likely to work, based on the views of all the people involved in setting it up and using it, how well people are feeling in themselves, the quality of their lives, how many feel they are more recovered, and what the system costs to run.
The Public Patient Involvement element of PARTNERS2 is integrated into the study. It is not a bolt-on aspect but instead part of the methodology, study management and steering groups. The study team comprises of economists, statisticians, trial specialists and also lived experience expertise.
Lived experience on the study

- SU researchers in all three research sites
- Lived experience posts include a national PPI co-ordinator and a SU Trainer
- SU and family members as advisors – recruited to Lived Experience Advisory Panels (LEAPs).
Role of LEAPs

The local LEAPs form a consultation group and meet every three months.

The LEAP members have been recruited from user / carer networks with a target of 10 members per site.

From the local LEAPs 3-4 representatives join national research meetings at key milestones in the study, attended by all researchers and other stakeholders.
LEAP member perspective and transition to SU Researcher

• Lived experience of relevant mental health issues as both service user and family member.

• Existing research expertise in a very different field.
Differing perspectives:

- As a LEAP member - an overview and regular snapshots of the PARTNERS2.

- As a researcher – involved on a regular basis across four different work streams.
Range of LEAP contributions

• Have a variety of different skill sets and backgrounds.
• Provide advice on materials for potential study participants.
• Enjoy a critical distance from the study.
Differing perspectives as LEAP member and researcher – an example:

• Trialling repeated measures as a LEAP member.

• Trialling outcome measures with LEAPs as a researcher.
Researcher perspective of LEAPs

• Become a vital part of project development
• Continuous dissemination of information

Challenges:
• Managing expectations and limitations to their influence
• How to retain a voice of LE at stakeholder meetings
• How to capture the impact of LEAP input
• How to continue with LEAPs going into a trial
Thank you
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Nicola Morant and Mike Davidson, UCL:

‘Peer or Researcher? Weighing forms of expertise in collaborative mental health research’
Peer or Researcher?
Weighing forms of Expertise in Collaborative Mental Health Research

Nicola Morant and Mike Davidson
UCL Division of Psychiatry
Two models of integrating lived experience expertise into research

Large Lived Experience Groups

- Diversity of lived experience prioritised
- Large numbers = broad spectrum of lived experience.
- Research experience / knowledge less important

Small numbers of peers

- Work as a peer researcher prioritised
- Role requires ability to understand / fit in with research process

PPI tasks / remit within academic-led mixed methods research projects:
- Input into research design; research processes; dissemination etc
CORE: Crisis Resolution Team Optimisation and Relapse Prevention.

• One part-time salaried public involvement co-ordinator (service user)
• Two related advisory groups:
  – Service users n=10-13
  – Carers n=7
AD-CARE: Acute Day Units as Crisis Alternatives to Residential Care

• One full-time peer researcher
• Small group of lived experience peers (2 service users, one carer) supported by McPin).
What does this type of involvement feel like?

- Different roles on each study
- CORE
  - Peer support worker, research assistant, working group member
  - ‘Changing hats’
  - Large research team from different backgrounds
  - Service user/carer involvement real, non-tokenistic, respectful, impactful
What does this type of involvement feel like?

- **AD-CARE**
  - Single integrated role
  - Which voice to use?
  - ‘Peer researcher’
  - How does this model of PPI feel different?
    - More ‘professionalised’ PPI participants?
    - Potential access to a different service user voice?
Large group vs. small group – Reflections...

- **Large group model = ?**
  - PEER research?
- **Access more voices**
  - diversity / representation?
- **Involvement can be flexible and spread thinly**
  - too thinly?
  - some tasks not easy for all
  - may need some research training input
- **Broader range of roles possible**
- **Needs sufficient resources:**
  - Large numbers of people = lots of co-ordination

- **Small group model = ?**
  - peer RESEARCH ?
- **Dependent on small group of people**
  - higher levels of commitment?
- **Does specific personal experience of a few get amplified?**
- **Role needs more knowledge of research processes from outset**
  - may suit more ‘professionalized peers’
  - is ‘authenticity’ of voice retained?
- **Easier to co-ordinate / integrate into research programme**
**Project details and Funding acknowledgements**

- **CORE**: [http://www.ucl.ac.uk/core-study](http://www.ucl.ac.uk/core-study)

- **Ad-CARE**: [https://www.ucl.ac.uk/psychiatry/research/epidemiology/ad-care](https://www.ucl.ac.uk/psychiatry/research/epidemiology/ad-care)
  - Acute Day Units (ADUs) as Crisis Alternatives to Residential Care (AD-CARE)”. Led by Prof David Osborn, UCL. NIHR Health Service and Delivery Research. £820,000. July 2016 – June 2019.

- This presentation presents independent research funded by the National Institute for Health Research (NIHR). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.
Steve Gillard, Rhiannon Foster & Lucy Goldsmith, Population Health Research Institute, St George's, University of London:

‘Co-production, lived experience and large multidisciplinary research teams: making it meaningful in practice’
Co-production, lived experience and large multidisciplinary research teams: making it meaningful in practice.

Steve Gillard, Rhiannon Foster and Lucy Goldsmith.
Why lived experience in research?

10 year+ SGUL tradition of researchers with personal (lived) experience of emotional distress and/or using mental health services as integral to our research teams

• More ethical
  – ‘Participants or their representatives should be involved wherever possible in the design, conduct, analysis and reporting of research’
    Research Governance Framework for Health & Social Care 2001

• A rights issue
  – ‘Nothing about us without us’
    Beresford, P. (2000) “Service users’ knowledges and social work theory: Conflict or collaboration?”
    British Journal of Social Work, 30:489–503

• Better research
  – Research done from experiential standpoints enables critique of dominant discourse
What do we understand by coproduction?

1. High value research decision making spread across the team
2. Different interpretations of data owned and understood in terms of ‘who we are’
3. Flexibility of method where scientific conventions constrain the input of team members
4. Critical reflection on how we did the research and why (rather than rigorous application of method)
5. Consideration given to ‘unevenness’ in coproduction and the impact of this on the knowledge produced
6. Outputs that report on how the knowledge was produced
Enhancing discharge from inpatient to community mental health care (ENRICH): a programme of research to develop, pilot and test peer support for discharge

<table>
<thead>
<tr>
<th>Workpackage</th>
<th>Design</th>
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<tbody>
<tr>
<td>1. Manualising the intervention</td>
<td>Systematic narrative synthesis review + expert panels</td>
</tr>
<tr>
<td>2. Developing a fidelity index</td>
<td>Review, expert panels + multi-site reliability testing</td>
</tr>
<tr>
<td>3. Piloting the intervention</td>
<td>Pilot trial in 2 Trusts (N=64; 4 month follow-up)</td>
</tr>
<tr>
<td>4. Trialling the intervention</td>
<td>Pragmatic RCT in 6 Trusts (N=590; 12 month follow-up)</td>
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<tr>
<td>5. Studying the impact on Peer Workers</td>
<td>Mixed method cohort study</td>
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Lived experience in the ENRICH team

2 x NHS Managers
Health Economist
Principle Investigator
Health Services Researcher
Voluntary sector
Peer worker
Trial Manager
2 x Service User Researchers
Lived experience lead
NHS Involvement lead
Professor of Psychiatry
Professor of Nursing
Professor of Health Psychology
Professor of Clinical Psychology
Health Economist
Medical statistician
Trial statistician
NHS Peer worker
Ideas about what lived experience can contribute

• Authenticity, different research questions, has implications for what service users can contribute to their own recovery (self help) and the recovery of others.

• Ideally changes the power balances.

• Socially negotiated identity: ‘I can only contribute meaningfully to research using my lived experience if my team agree I can contribute meaningfully to research using my lived experience’

• ‘My contribution is only meaningful if the team agree that including a lived experience perspective in this project is meaningful’

• **Implications:** May take more time as more views are considered. The final product may be a less conventional piece of work.
Expectations of the contribution of lived experience

• Breaking down ‘us and them’ (homogeneity) vs Service users & lived experience making a unique contribution in a multidisciplinary team.

• Lived experience; ‘experts by experience’

• Design and conduct research or influence pre-existing plans?

• Disclosure and using lived experience – managing the discomfort of others vs information easily received as a welcome contribution.
Victims or Survivors?

• Parallels between service user research and dialogues about identity in mental health
• Epistemology (body of knowledge)
• Survivor research contributions are not a solitary activity.
• Flattening a hierarchical structure.
• Time for support, clear values, respect.
Service User Researchers at St George’s: Semantics

<table>
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<tr>
<th>Role</th>
<th>Knowledge</th>
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<tr>
<td>Service User Researcher</td>
<td>Experiential knowledge</td>
</tr>
<tr>
<td>Survivor Researcher</td>
<td>Survivor knowledge</td>
</tr>
<tr>
<td>Experts by experience</td>
<td>Lived experience</td>
</tr>
<tr>
<td>Peer Researcher</td>
<td></td>
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Example of Knowledges Colliding (happily?)

• **Brief Psychiatric Rating Scale** – used as one of the data collection tools for ENRICH. 24 items to rate psychiatric symptoms (12 interview format, 12 rated based on observed behaviour and speech during interview).

• Symptoms ranging from depression, elevated mood, anxiety, grandiosity, suspiciousness, guilt.

• **Service User Researcher’s perspective**: 1) Clinical measure focusing on symptoms and deficits from a very psychiatric lens; 2) ‘us and them’ or ‘researcher and researched’ means less equal relationship; 3) Very subjective from perspective of researcher without any documentation to account for that subjectivity; 4) for me it mirrors some of the power imbalances that can be experienced as a service user – lack of power, voice and choice.

• **Other researchers’ perspectives**: 1) provides a comparable measure that other studies of similar nature have used; 2) we need to be able to describe our population in clinical terms to be published in an appropriate journal; 3) it may be an additional way to check that our intervention is not making any participants’ symptoms worse.
So what have we done?

• We have a support network within the team and an experienced SUR (Sarah) to support us, help to voice our concerns (if we don’t feel we can!) and continue monitoring the process of using the tool and the impact that has on us and the people who take part in our research (constant feedback).

• We went through the items on BPRS (not fixed standardised items) and re-wrote our own set of questions that we felt were more service user friendly.

• SUR training – we have arranged 4 meetings so far to explore our feelings in relation to all the issues that come from being a SUR: staying well while we’re working, supporting each other, continued reflection on how our personal experience may impact us using the scale, explored our worries about using the BPRS (what if.....), keeping dialogue open, discussion about writing papers that might be useful for other SURs?
How does all this FEEL?

• Me: concerned, biggest worry is that I don’t want to do to someone else, any of the negative things that have been done to me. Disempowerment, lack of voice, being judged, watched, not feeling equal.

• Other SURs: Lucy? Sarah?

• Steve’s perspective?
The ENRICH Team

St George’s, University of London - Rhiannon Foster, Sarah Gibson, Steve Gillard, Lucy Goldsmith, Jacqui Marks, Michael Ussher, Sarah White

South West London & St George’s Mental Health NHS Trust - Shalini Patel, Miles Rinaldi

Sussex Partnership Foundation Trust - Ruth Chandler

Together for Mental Wellbeing – Jessica Worner-Rodger

City University – Sally Barlow, Alan Simpson

Huddersfield University - Mike Lucock

Nottingham University - Julie Repper

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