

KING'S
College
LONDON

Lived Experience

and Research Impact



ESRC Centre for Society and Mental Health: Our Vision



research to promote and sustain good
mental health in communities

Session Overview



- What is Lived Experience Engagement
- Why embed it in your research projects
 - How to do it
- Food for Thought

The Public Engagement Context



'Public engagement describes the myriad of ways in which the activity and benefits of higher education and research can be shared with the public. Engagement is by definition a two-way process, involving interaction and listening, with the goal of generating mutual benefit.'

[NCCPE's definition of Public Engagement](#)

'We must break down the barriers between research and innovation and wider society. We must engage widely to build shared understanding between those who consider themselves to be part of the research and innovation system and those who do not.'

[Ottoline Leyser, Chief Executive, UK Research and Innovation](#)

Participatory Action Research (PAR)



Participatory action research (PAR) is an approach to research that seeks to situate power within the research process with those who are most affected by a programme [or issue]. The intention is that the participant is an equal partner with the researcher.

- [CSMH Research Methods Toolkit](#)

Participatory research is a collaborative approach to research that involves the people whose lives are affected by the issues being researched. They are included equitably as partners throughout the research process. The aim is to improve people's lives and bring about social change.

- [King's Research and Innovation](#)

Lived Experience Engagement: A note on language



- People with lived experience
- Lived experience experts
- Experts by experience
- Service users
- Survivors
- Always ask!

Lived Experience Engagement: Why do it



- Research that is seen as credible, trustworthy, responsive and responsible
- Improve outcomes for individuals and communities affected by your research topic
- Make a strong impact, including policy impact

Lived Experience Engagement: How to do it



- Consultation
- Co-production of research
- LE-led research

Lived Experience Engagement: Things to consider



- Recruitment
- Establishing equitable working practices
- Safeguarding
- Compensation, acknowledgement, development opportunities
- PEOPLE > PROGRAMME

Lived Experience Engagement: Challenges



- Challenge to entrenched working styles and norms
- Lack of institutional support / cumbersome systems
- Discomfort – critical friend

Lived Experience Engagement: Challenges

'It's almost like you have to take the hand of the people in power and say 'let me take you to the edge of how bad things are, and don't look away. You need to see this to understand how bad things are'. They won't go there by themselves.'

CSMH LEAB Position Paper

Reflections to take away

Survivors aren't a monolith

Reflections to take away

We discussed at length the dilemma of being involved because of our lived experience and then having our skills, opinions or expertise diluted, devalued or dismissed as a result.

Sometimes this is because people assume that we only have our lived experience to offer when we might also have research and other skills.

Reflections to take away

‘I was doing the research, not being researched.’

A generic framework to think about impact

What is the problem you are trying to fix/the change you want to make?

Inputs

People
Grants
Facilities

Activities

RCTs,
longitudinal
studies,
qualitative
interviews,
systematic
reviews,
prediction
models, etc

Outputs

Identify
causal
factors,
treatment

Outcomes

Cause others
to develop
line of
research,
develop
therapies,
improved
research
methods

Impact

Better health
outcomes,
reduce costs,
new jobs,
raise
awareness,
new
legislation

Evidence

Objective
verifiable
proof of
change,
& how
the
research
led to the
change

Impact Template

Inputs	Activities	Outputs	Outcomes	Impact	Evidence
			.		

What do you need to do to move from inputs to impact:

- Inputs:
- Activities:
- Outputs:
- Outcomes:
- Impact:

Stay in touch

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