

Learning from phase one

Introduction

- The purpose of this phase of the project was to find out what we currently know about lived experience engagement.
- We started by thinking about what we know from current research literature – but because we are aware that research doesn't always reflect real life experience, we took our findings from that literature review to some sense check workshops in Selby with VCSE and statutory organisation partners.
- In our report, we bring findings from the literature review and sense checking together with the responses to questionnaires from VCSE organisations and NAVCA members
- We believe that the findings from our year one research firstly show both the potential of lived experience engagement, and the challenges of doing it well.
- And secondly, suggest ways that universities and VCSEs can work together to create research projects that are relational and not extractive.
- In our report, we say that that looks like research that 'builds relationships, strengthens confidence, and creates change that lasts'.
- The report gives more detail, but today I'd just like to draw your attention to some of our headline learning around 1. How organisations think about lived experience 2. The challenges and

barriers to lived experience engagement and 3. What ‘good’ lived experience engagement might look like

- And then share with you what we’ve identified as useful learning for other organisations.

How organisations think about lived experience engagement

- Across Selby and East Yorkshire, we found that there is a shared enthusiasm for lived experience engagement and a shared belief in its benefits for individuals, organisations and wider society.
- But that VCSEs perceptions of their expertise in lived experience engagement was varied: 69% of organisations rated their performance at engaging lived experience at 7 out of 10 or higher
- 68% of organisations said they would welcome support with their lived experience engagement
- Organisations welcomed the opportunity to learn and share around lived experience

Challenges and barriers

- Despite this enthusiasm and will, there are significant barriers and challenges
- There’s a whole list of these in the report, but they include:
 - Existing pressures on organisations that are stretched to the limit
 - Short funding cycles that don’t leave time for participatory work

- Financial impact (such as payment for staff and participants, meeting resources, translations)
- Reliance on volunteers
- Anxiety about getting it wrong

What 'good' looks like

The combination of our literature review, sense checking and surveys suggest that 'good' lived experience engagement is founded on...

1. Partnership: on-going not one-off engagement
2. Clarity of purpose from the outset: people know why their voice is being sought and what will happen next
3. Safety and support: participants are emotionally and practically supported
4. Reciprocity: people see the value of their input and receive feedback
5. Fair reward: participation is recognised through payment/benefit; staff are not working unpaid overtime
6. Representation: diversity and inclusion are actively sought and monitored
7. Learning culture: organisations and individuals reflect and adapt

Learning for other organisations

To draw the report together, we've identified seven learning points for other organisations.

1. Start with relationships, not research questions – investing in relationships is the foundation

2. Value lived experience as expertise – it's not anecdotes, it's expert knowledge from real life
3. Embed engagement in everyday practice – don't think of it as a special project
4. Create safe and supported spaces – look after people through trauma-informed practices, aftercare and clear boundaries
5. Share power and decision making – listen, negotiate and be open to change
6. Learn together – be open, be curious, be respectful
7. Show the impact – let people see what change their participation has made

ERG section:

Creation of an **Evaluation and Research Group** led by CERT to focus on evaluating and learning from the Lived Experience Group. Comprising members of Up for Yorkshire, CERT and community researchers, the Group will:

- Co-design evaluation tools.
- Develop shared measures of impact.
- Train community members in participatory research.
- Aim to produce accessible reports and learning resources for future dissemination.