project change

FREE DISCUSSION GUIDE · NO. 02

02

Why lived experience matters:

from story to expertise

A discussion guide for organisations that want lived experience to influence decisions, not simply illustrate them.

People should not have to hand over their hardest moments just to earn a seat at the table. Lived experience is knowledge, not a story bank.

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START HERE

Lived experience is a form of knowledge.

People who live through a service, system, identity, condition or set of circumstances know things that can be difficult to see from the outside.

They notice where policy collides with reality. They experience the hand-offs, forms, waiting, language, assumptions, workarounds and unintended consequences that may be invisible from an organisational chart.

Lived experience does not replace professional expertise. It challenges the idea that professional expertise is the only expertise in the room.

It also does not make one person representative of everyone. Experience varies. Perspective varies. People interpret similar experiences differently.

Experience

What someone has lived through, encountered or navigated.

Experiential expertise

Knowledge that can grow when people have space to reflect, connect patterns, understand context and apply what they know to decisions.

DISCUSS

Where does your organisation currently treat lived experience as evidence? Where does it treat it mainly as a personal story?

BETTER DECISIONS NEED DIFFERENT KINDS OF KNOWING

Three lenses are stronger than one

01

Lived expertise

What it is like to encounter the system, service or issue in real life. Where friction appears. What makes sense. What does not.

02

Practice expertise

What staff, practitioners, volunteers and delivery teams know from doing the work and navigating operational reality.

03

Research & evidence

What data, evaluation, research, rights frameworks and wider evidence can tell us beyond individual experience.

None of these automatically wins.

Good decisions are made by bringing different forms of knowledge into useful tension. Lived experience can expose a gap in the data. Evidence can show whether an individual experience is widespread. Practice knowledge can reveal what implementation will take.

Different expertise. Shared problem.

The goal is not a hierarchy of knowledge. It is a fuller picture.

WHY IT CHANGES THE WORK

What lived experience can reveal

The gap between intended and experienced

A process can look simple on paper and feel impossible to the person navigating it.

Hidden assumptions

Language, eligibility rules and service design often contain assumptions about what people know, have access to or are able to do.

Unintended consequences

A well-meant policy can create shame, extra work, repeated disclosure or a barrier nobody intended.

What actually matters

Organisations can measure what is easy to count rather than what people value. Lived experience can reframe success.

Possibilities professionals may miss

People develop workarounds, ideas and practical knowledge through using systems every day.

Whether change is felt

An organisation can complete an action plan without the experience on the other side of the system changing at all.

THE EXTRACTION PROBLEM

Bad lived experience work can look very respectable.

It can have a steering group, branded slides and a photograph at the end. The question is what happened to people's knowledge.

1

Story extraction

People are repeatedly asked for intimate stories because emotion is compelling, even when those details are not necessary to make the decision.

2

Representation theatre

One person is expected to speak for an entire community, then blamed when other people disagree.

3

Influence after the fact

People are invited in once the important decisions are already made and offered choices around the edges.

4

Free expertise

Everyone else in the room is there because it is their job, while the person with lived experience is expected to contribute unpaid “because it matters”.

5

The disappearing feedback loop

People contribute and never find out what changed, what did not, or why.

DO IT BETTER

Eight conditions for meaningful lived experience

Ask for expertise before you ask for autobiography.

Sometimes personal stories are freely chosen, powerful and important. The point is that organisations should not require trauma or disclosure as the price of being listened to.

- ✓ **Purpose:** be clear about why lived experience is needed and what it can influence.
- ✓ **Choice:** nobody should have to disclose more than they want to in order to contribute.
- ✓ **Payment:** value people's time and expertise fairly, with expenses and practical barriers considered too.
- ✓ **Preparation:** give people enough context to participate as decision-makers, not surprise witnesses.
- ✓ **Access:** offer different formats, times and ways to contribute.
- ✓ **Multiplicity:** seek a range of perspectives and never imply one person's experience is universal.
- ✓ **Power:** involve people early enough to affect priorities, options and decisions.
- ✓ **Accountability:** close the loop. Explain what changed, what did not and what happens next.

USE THIS WITH YOUR TEAM

Where does lived experience enter the decision?

Choose one policy, service or programme. Map where lived experience currently appears across its life.

Setting priorities ☐	Understanding the problem ☐	Research ☐	Generating ideas ☐
Choosing options ☐	Testing ☐	Delivery ☐	Evaluation ☐

1 **Where are people involved now?**

Mark the stages honestly. “We ran a survey” is a method, not automatically influence.

2 **Where is their knowledge absent?**

Which decisions are made entirely through professional, financial or organisational lenses?

3 **Where is involvement too late?**

Identify points where people are asked to respond after a direction has effectively been chosen.

4 **What would meaningful influence look like?**

Pick one stage and redesign it so lived experience changes the decision, not just the wording.

TAKE IT FURTHER

From listening to change

The strongest lived experience work is not measured by how many stories were collected. It is visible in what the organisation understands, decides and does differently.

Want to build this into your organisation?

ProjectChange helps organisations create better lived experience practice, participation frameworks, structural listening and co-design. We can train teams, review what you already do or work alongside you to build something better.

projectchange.scot/work-with-us →

USEFUL SOURCES AND FURTHER READING

Scottish Government, National Care Service co-design: lived experience and human rights at the centre, recognising people who use and deliver services as experts in how they work. gov.scot

Design Council, Framework for Innovation: inclusive, people-centred, collaborative and iterative design. designcouncil.org.uk/resources/framework-for-innovation

The Promise Scotland, Story of Progress, including an Experience Lens alongside organisational and national progress. thepromise.scot/supporting-plan-24-30/story-of-progress

This guide deliberately uses "lived experience" broadly. Different communities and individuals use different language, and not everyone describes their knowledge as expertise. Ask people what works for them.