Engaging Lived Experience

A research partnership between Up for Yorkshire and York St John University: Phase 1 - Insights and Next Steps

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insight through experience

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Introduction

In September 2024, Up for Yorkshire (UfY) and The Converge Evaluation and Research Team (CERT) secured a Community Research Grant from York St John University's Institute for Social Justice, to explore the questions:

> How do we better listen to, capture and represent the voices of people with lived experience in order to have a meaningful impact on policy and the design of community services?
>
> How can we support those with lived experience to participate purposefully?

The collaboration set out to explore how voluntary, community and social enterprise (VCSE) organisations in Selby and North Yorkshire can meaningfully engage with lived experience — and how universities can work alongside them to support, evidence and strengthen that engagement.

This report shares the story, insights and next steps from a year-long partnership and forms part of a growing national movement that recognises that people's lived experience is expertise. When communities are listened to, and their voices are valued alongside professional knowledge, services can become more effective, inclusive and sustainable.

The findings from our year one research show both the potential and the challenges of doing that well. They also point to an emerging model for how VCSEs and universities can partner in ways that are relational, not extractive — where research builds relationships, strengthens confidence, and creates change that lasts.

Project partners

Up for Yorkshire - UfY is a local support and development organisation and community anchor, based in Selby, North Yorkshire, delivering a wide range of community activities and support across a number of key areas, including: employability, physical and emotional wellbeing, and food and financial inclusion.

As an infrastructure organisation, a significant proportion of UfY's work aims to enable the wider local VCSE sector to grow and flourish, ensuring the delivery of high quality services that meet the needs of local residents.

Converge is a creative learning community based at York St John University, offering university-based educational courses to adults in York with mental health challenges. The foundational principles of Converge are that participants are students not patients; and what is offered is education not therapy. The **Converge Evaluation and Research Team** (CERT) is group of Converge student researchers with lived experience of mental health challenges. Since 2017, CERT has become a formal York St John University research group, specialising in participatory evaluations of community mental health related projects across the country.

A detailed account of phase 1 can be found here: https://upforyorkshire.org.uk/research/

Background: why context matters

This research project took place against a backdrop of rapid social, economic and political change in North Yorkshire — a largely rural area that combines affluence with hidden inequality and structural disadvantage.

Rural realities

In many communities across Selby and North Yorkshire, geography shapes opportunity. Long distances, limited public transport and patchy digital connectivity all make it harder for people to access services, socialise and connect with others or participate in wider public life.

Rural deprivation can be invisible, with poverty and isolation often hidden behind closed doors. High fuel costs, lack of affordable housing and casual or shift work can all contribute to insecure living conditions.

Economic pressures and community response

The Covid pandemic, followed by the cost-of-living crisis and its ongoing impact, has meant that local VCSE organisations have frequently become the front line of support — from food banks and warm spaces to advice, wellbeing and social connection. Yet many VCSE organisations themselves struggle with limited funding, short-term contracts, recruiting and supporting volunteers and staff burnout. Despite this, there is increasing demand as more and more community based support is delivered via a network of VCSE organisations.

Political and policy change

At the same time, local governance has undergone major transformation. The creation of the new North Yorkshire Council and the York and North Yorkshire Combined Authority present both challenges and opportunities for the VCSE sector. While these developments bring the promise of more integrated, place-based decision-making, they also create uncertainty:

- Will smaller local voices be heard in larger structures?
- How can VCSEs influence strategy without losing their independence?
- What does genuine partnership look like in practice?

In this context, lived experience becomes a vital bridge between systems and citizens. It provides real-world evidence that can ground policy, shape services and build trust.

The Partnership Approach

Key to this research collaboration has been the partnership between UfY and York St John University with a shared commitment: to explore how communities' lived experience can shape VCSE activity and decision-making.

We believe that when people are empowered, and their voices are heard and understood, we can develop services that better meet their needs. From the outset we knew that there is good practice out there and ambition to improve things among VCSEs and statutory service organisations. We wanted to find out how VCSEs, and system partners currently work with people with lived experience in order to learn from it and then co-develop resources and support to help organisations to self-assess, guide and improve the quality of their relationships with those with lived experience.

To widen our partnership and opportunity for learning and sharing, the research collaboration delivered a number of key elements:

1. A steering group of local VCSE, statutory and academic partners, providing project oversight, feedback and connections across sectors.
2. An academic literature review examining best practice in lived experience engagement. The full literature review can be found here: https://upforyorkshire.org.uk/research/
3. A series of 'sense checking' focus group workshops to examine the findings from the literature review; exploring and considering its application and impact on individuals' and their organisations' daily activity/processes/ understanding.
4. A facilitated Social Imagination Workshop held in Selby, inviting creative ideas and providing participants with the opportunity to view their current lived experience activity from a different perspective.
5. Surveys distributed locally through UfY networks and nationally via NAVCA (the National Association for Voluntary and Community Action).

This report combines learning from the academic literature review, the 'sense checking' focus group workshops and the two surveys.

This mix of research methods allowed us to capture both breadth and depth — exploring how engagement happens now, what gets in the way, and what support VCSEs believe they need to do it better.

The Community Research Grant programme created an opportunity to engage in participatory research. The aim was not to produce another academic paper, but to spark practical change — the kind that can make a lasting difference on the ground.

What does 'lived experience engagement' mean to you?

A range of definitions of 'lived experience' were offered by survey respondents[1] in this project. The most common themes include 'active listening' to better understand people; valuing people with 'first hand' lived experience; and creating opportunities for 'meaningful inclusion':

To me, it means seeking the views, stories and involvement of people living with whatever condition that is the focus of your service. [Community Healthcare Team].

Having the opportunities to share your views and experiences based on who you are and what you have experienced in your life. [Community Support].

Actively listening and proactively responding. Creating opportunity for meaningful inclusion of lived experience voice. [Domestic Abuse After-Crisis Support].
It means listening properly to the people we have any kind of relationship with. Understanding their life experiences what they have experienced throughout their life. How it's affected them. [Health and Wellbeing].

"Lived experience engagement" means actively involving people who have first hand experience with an issue—like mental health, homelessness, or disability—in shaping the policies, services, or research that affect them. It's about truly listening to their voices, valuing their insights, and making sure decisions aren't just made for them, but with them. [Environment].

Actively involving a wide range of people who have direct, personal experience of a particular issue/illness/ barrier/disability etc in the design and delivery of projects, organisations, campaigns etc, ensuring their expertise, insight and opinions form a core part of any of the work we do as an organisation. [Health and Wellbeing].

[1]In this report, the sector of the respondent is in square brackets (where available)

What we learned

Strong enthusiasm and shared belief

Across Selby, North Yorkshire and beyond, organisations expressed a clear commitment to involving people with lived experience. Most VCSEs see it as a key part of their mission and identity and there is a confidence in the benefits of engaging in lived experience work by VCSEs and statutory partners, particularly community cohesion, resilience and wellbeing.

- 59% of local survey respondents said that lived experience is "very important" to their work.

"It is essential to have the input to ensure services remain relevant and inclusive." [Community Support].

"Listening helps us avoid dead-end solutions that don't work in practice. People know what's needed — if only we'd listen properly" [Health and Wellbeing].

Motivations included:

- **Valuing lived experience: "**It's incredibly valuable when done right" [Health and Wellbeing].
- **Improving relevance and responsiveness of services** for example: "It is essential to have the input to ensure services remain relevant and inclusive" [Community Support]." Parents of children with disabilities and impairments are uniquely placed to inform the charity about the needs & wants of the child & the whole family" [Disabilities].
- **Understanding needs:** for example: "Without involving people, how do we know what their needs are, thus leading to pointless interventions and funding spent incorrectly" [Health and Wellbeing] and "Understanding their life experiences what they have experience throughout their life. How it's affected them [Health and Wellbeing]".
- **Accountability:** for example: "We can't possibly offer the service we dedicate ourselves to without fully involving people with lived expertise, they are a hive mind of wisdom that helps us continually improve and they hold us accountable" [unspecified organisation].
- **Empathy:** Being able to relate to and empathise with individuals who may be struggling for whatever reason [Community Support].
- **Influencing policy: "**That means from small scale things to policies that affect people, to large scale service coproduction and strategy. For us, it's about talking to people beyond our own client group wherever possible and trying to [get] significant engagement - i.e not designing a service based on the experience of 10 people" [Health and Wellbeing].

Perceptions of competence at lived experience engagement

The perception of expertise in lived experience engagement was varied, with some organisations reporting high levels of expertise and others reporting a lack of expertise.

- 69% of organisations rated their performance at engaging lived experience at 7 out of 10 or higher.
- 68% of organisations indicated that they want support with their lived experience engagement.

"It is essential to have the input to ensure services remain relevant and inclusive [Community Support]"

VCSE respondents also welcomed the opportunity to learn and share experience of lived experience engagement, with the chance to access tools, case studies and partnerships to help them turn values into action.

Barriers and challenges

The will is strong, but the way isn't always clear – it is more about the 'how' than a lack of desire to do it. Findings from the first year of research reveal consistent barriers across the sector to undertaking lived experience engagement, in particular, capacity and resources.

In our sense checking focus groups and surveys, participants told us that:

- Organisations (especially small ones) are **stretched to the limit**. Staff and volunteers juggle multiple roles, leaving little time for reflection or structured engagement.
- **Funding cycles are short**, and there's rarely budget for participatory work.
- **Perceptions of time** (for example, not having enough time) are seen as significant barriers to trying lived experience engagement.

"Time and capacity pressure. Lack of Infrastructure or Processes. Lack of process for gathering, recording and acting on lived experience insight. Engagement is often ad hoc rather than embedded into planning, service design, or evaluation. I believe that engagement is seen as a requirement rather than a genuine opportunity to shape services" [Health and Wellbeing].

- **Financial impact** of lived experience engagement is seen as a barrier, including staff time payment, payment for lived experience participants' time, meeting resources, and translations.
- **VCSE reliance on volunteers** was an important factor: whether there is enough resource to support lived experience engagement Is crucial. The necessary skills, training and support needed for volunteers to undertake this role needs to be taken seriously.
- **Confidence and skills** - some teams lack training in facilitation, trauma-informed approaches or safeguarding. There's anxiety about "getting it wrong" or causing distress when inviting people to share personal stories.

"I think all of our staff are individually good at drawing lived experiences out of our clients, through taking the time and having the patience to build deep, trusting relationships, and using individual lived experience to help each client. However, I don't think that we properly compile all of the lived experiences together and integrate the subsequent lessons into our work and our working practices as an organization" [Community Support].

- **Risk of harm** by conducting poor coproduction was seen as a barrier by some participants.
- **Communication** was seen as important, for example, in supporting people to see whether opportunities are right for them.
- **Limited representation and reach** can unintentionally reproduce inequality. The same confident, connected individuals are often over-represented, while those most affected by issues remain unheard. Focus group participants recognised the need to widen engagement to avoid only listening to the same voices.
- **Practical barriers** such as transport, childcare, time, and payment for participation continue to be major hurdles.
- Our literature review also told us that:
- **Bad experiences can linger**: participation challenges people (Newton 2022, Hatzidimitriadou et al. 2012)
- **Power dynamics** mean that even in well-meaning settings, people with lived experience may feel undervalued or tokenised or unsure whether their contributions will lead to change (Arnold et al. 2018, Harden et al. 2015, Hatzidimitriadou et al. 2012; Bagnall et al 2024)

"From my experience when I have engaged with people with lived experience, they may be invited into conversations but not given real influence or feedback loops very well. It then begs the question to be asked by the patients... "What are we doing it for?" [Health and Wellbeing].

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The benefits of doing it well

Despite these challenges, the research literature review, sense checking focus groups and questionnaires demonstrated that the benefits of genuine lived experience engagement can be transformative — for individuals, organisations and communities alike.

- **For Individuals** — it can be transformative and life-changing; offer hope for the future; provide inspiration and meaning and purpose in life; increased motivation and confidence; agency; and having a voice (Newton 2022, confirmed in sense checking focus groups).
- **For Organisations** — authenticity; improved access to information; stronger support for innovation and change; greater knowledge and expertise; valuable perspectives that inform strategies; ensuring that services are relevant and effective; smart solutions to complex problem; communication and networking; evidence based; and increased legitimacy (Newton 2024, confirmed in sense checking focus groups and surveys).
- **For the Wider System** — enables society to challenge the social systems, structures, and narratives that define people; strengthen community wellbeing and resilience; combats stigma and discrimination; increased participation in work, training and volunteering; increased resilience and viability of community services; savings to public budgets; managing expectations and reducing inequalities (Newton, 2024)

For some, lived experience work is transformative and life-changing. The skills, knowledge, and experience that people gain (or regain) from doing lived experience work frequently helps them to move forward with their lives and take hold of opportunities that fulfil their potential and aspirations (Newton, 2022).

What "good" looks like

Drawing on our literature review, conversations in our focus groups and the survey responses, we have identified several common ingredients of effective lived experience engagement:

1. **Partnership** – engagement is understood to be ongoing, not one-off
2. **Clarity of purpose from the outset** – people know why their voice is being sought and what will happen next. This includes:
   a. Considering at the beginning which people need to be involved
   b. Explicit management of expectations
   c. Clear boundaries and guidelines
   d. Sufficient knowledge, skills, commitment and resources (especially funding and time) to see things through
   e. Accessible planning, design and implementation processes.
3. **Safety and support** – participants are emotionally and practically supported. This includes:
   a. Individual supervision and mentoring
   b. Training and feedback for people with lived experience
   c. Ensure language is accessible and not stigmatizing
4. **Reciprocity** – People see the value of their input and receive feedback. This includes:
   a. Accountability and open feedback
   b. Learning together how to make things work through reflection by all parties.
5. **Fair reward** – This includes participation being recognised through payment or other meaningful benefit and considering whether staff may be working unpaid overtime.
6. **Representation** – Diversity and inclusion are actively sought and monitored.
7. **Learning culture** – Organisations and individuals reflect and adapt. This includes:
   a. Sharing information and good practice
   b. Participants in the focus groups liked a ladder model for engagement (for example, Arnstein, 1969) which offers progressive steps towards fully engaging lived experience. This provides the opportunity to learn, build in good practice, without the pressure to do everything immediately
   c. Demonstrating worth via comprehensive evaluation
   d. Identifying and sharing best practice
   e. Organisational culture in which people feel safe to discuss what happened when things go wrong.

Learning for Other Organisations

From this first phase, we have identified several key lessons for VCSEs and partners who want to embed lived experience meaningfully.

1. Start with relationships, not research questions

   Effective engagement begins with trust. People are more likely to share experiences when they feel respected and safe. Investing in relationships is foundational.

2. Value lived experience as expertise

   Lived experience is not anecdotal — it's expert knowledge drawn from real life. When combined with professional and academic insight, it creates a richer, more complete picture.

3. Embed engagement in everyday practice

   Rather than separate "consultations," lived experience should shape everything — from governance to service design. Even small steps (like feedback loops or advisory panels) make a difference.

4. Create safe and supported spaces

   Sharing personal experiences can be empowering but also emotionally demanding. Organisations should prioritise trauma-informed practice, clear boundaries and aftercare.

5. Share power and decision-making

   True partnership involves listening, negotiating, being open to change and sharing control.

   "Involving people with lived experience is listening to a diverse range of people's views and experiences. It's not just about listening; it's about ensuring they are involved in projects and opportunities from the very inception and allowing equal contribution." [Health and Wellbeing].

6. Learn together

   Partnerships between universities and VCSEs can be mutually beneficial when both sides are open, curious and respectful. Academic rigour and community insight are complementary, not competing forces.

7. Show the impact

   Communities are more willing to engage when they see evidence that their voices make a difference. Closing the loop — "you said, we did" — builds trust and motivation.

Phase Two: Research into Action

From the outset partners were clear that we didn't want the research to just end with a report and if successful it would mark the start of further collaboration and development of practice. With follow-on support from the Institute of Social Justice's Community Research Grant programme, over the next 18 months steps will include:

1. Establishment by Up for Yorkshire of a Selby **Lived Experience Group** - a new network of local residents, initially comprised of approximately 15 people with diverse lived experiences, who will explore key themes proposed by community and statutory partners. Based on our learning from phase one, members will receive training, support and payment for their contributions.
2. 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.
3. Shared Learning and National Impact

The partnership plans to share its learning widely — through conferences, national networks (like NAVCA) and accessible toolkits.

By testing a model informed by this research collaboration, our aim is to enhance how lived experience is embedded across the VCSE sector and work with system partners, demonstrating the value in combining local action with academic insight.

Conclusion

The first year of collaboration and research has brought a richness to our experience, confirming the realities of practice but reasserting the significant benefits of prioritizing, enabling and valuing lived experience engagement, for individuals, for organisations and for the wider system.

Better, and more informed decision making has also been recognised as a benefit from lived experience engagement. When people with lived experience are involved in decision-making, they can 'speak truth to power'. Their perspectives bring a diversity of thought that can lead to more robust, better decision-making as they are grounded in the reality of their own life (Man et al., 2019; Newton, 2022; Newton, 2024).

The literature review, stakeholder and resident engagement and conversations have demonstrated that co-production is both powerful and complex. It takes time, trust, and a willingness to be open to change. But the rewards are huge.

Our ambition was always to ensure that the research outcomes catalyse change and for Up for Yorkshire, the next step is to embed the principles emerging from this work across all strands of our delivery — from organisational strategy to front-line support. This research collaboration represents a critical step in the evolution of our practice and we look forward to sharing the outcomes of this work as we continue to learn, innovate and evaluate, working towards a Lived Experience Engagement Network for North Yorkshire that brings confidence, capacity and skills and connection to ensure lived experience is at the heart of every organisation.

Further information

For further information about this work, please visit Up for Yorkshire's website: www.upforyorkshire.org.uk.

You can also find out more about York St John University's Institute for Social Justice and the Community Grants Programme here: Community research grants | York St John University[2] and listen to our podcast, *Conversations in Social Justice*, Season 4, Episode 13: Giving a Policy Voice to People With Lived Experience: Conversations in social justice | York St John University[3]

To discuss the outcomes of this research or become part of the emerging Lived Experience Network, please contact:

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Up For Yorkshire is the working name for Selby District Association of Voluntary Service (AVS). Registered Charity Number: 1146109. Company Limited by Guarantee Number: 07565045

[2] https://www.yorksj.ac.uk/research/institute-for-social-justice/community-research-grants

[3] https://www.yorksj.ac.uk/research/institute-for-social-justice/conversations-in-social-justice

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