Engaging lived experience in VCSE activity – phase 1 detailed account

A collaboration between Up for Yorkshire and The Converge Evaluation and Research Team



Contributors:

Chris Hailey-Norris and Bryony Boyle, Up for Yorkshire
Dr Amy Skinner and Ruth Lambley, York St John University, Institute for Social Justice; CERT

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Converge Evaluation and Research Team
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Est. 1841 YORK ST JOHN UNIVERSITY

Institute for Social Justice
York St John University

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This report contributes to a wider project in between the Converge Evaluation and Research Team (CERT, York St John University) and Up for Yorkshire (UfY) funded by the Institute for Social Justice. The project addresses:

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 Institute for Social Justice works across York St John University to facilitate social justice research, projects and partnerships that help us to pursue and promote a fairer society. **Community Research Grants** support partnerships between York St John and the community.

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** 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, specializing in participatory evaluations of community mental health related projects across the country. CERT also conducts its own participatory based, coproduced academic research. CERT researchers use the insight they have from their lived experience to inform their research practice. CERT has considerable experience of working with community groups in evaluation and research. For more information about CERT.

Up for Yorkshire (UfY) is a local support and development organization 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. UfY has a commitment to creating inclusive, vibrant communities where everyone can thrive. Their work is underpinned by a number of core values: diversity, collaboration, openness and kindness and authenticity. As a local infrastructure organisation, UfY strives to support and strengthen the VCSE sector to deliver high quality services and meet the needs of local residents. UfY was recently awarded the Local Infrastructure Quality Accreditation Award.

Headline learning

1. Enthusiasm and support for lived experience engagement from both VCSEs and statutory partners.
2. Perception of benefits of engaging in lived experience work by VCSEs and statutory partners, particularly community cohesion, resilience and wellbeing.
3. Perception of expertise in lived experience engagement was varied, with some organisations reporting high levels of expertise and others reporting a lack of expertise.
4. Perception that concerns related to risk or harm is a key barrier to lived experience engagement.
5. Management of expectations is seen as important.
6. Broad agreement among the focus groups with the literature. Some language was seen as contentious. Some findings were challenged. The focus group reflected the findings that lived experience is nuanced and complex and can't be captured in soundbites.
7. One area missing from the research was the financial impact of lived experience engagement, especially related to UfY's rural 'constituency', staff time payment, resources, need for translations, etc.
8. Another area seen as missing from the research was time (relating to the whole of lived experience projects). Perceptions of time (for example, not having enough time) are seen as barriers to participation in lived experience projects.
9. Communication was seen as important, for example, in supporting people to see whether opportunities are right for them (related to Social Imagination workshop and the beautiful invitation: perceiving what your involvement could be).
10. VCSE reliance on volunteers was an important factor: have volunteers got enough resource to support lived experience engagement? Do volunteers require training?

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1. Introduction

There are limitations to the way that most voluntary, community and social enterprises (VCSEs) and public sector organisations currently approach community (lived experience) engagement.

Despite aspirations for coproduction and codesign, currently, processes often rely on individuals coming forward to participate. This means the same voices being heard each time: many people simply never come forward to engage. Up for Yorkshire (UfY) and CERT want to find a more equitable mechanism to allow UfY and the wider VCSE sector, to better listen to and value lived experience. Better engagement should lead to higher quality and more appropriate services which better meet people's needs and save resources via greater efficiency.

Embedded within social justice values of empowerment, voice and feeling heard and understood, better engagement should lead to higher quality and more appropriate services which better meet people's needs.

As an organisation, creating an informed, structured and supportive mechanism for gathering and listening to lived experience will help UfY and the organisations it works with to better ensure services and projects are genuinely meeting local needs. This includes responding appropriately to what is important for those people.

In addition to being more ethical, improvements in the way VCSE organisations work with lived experience will enhance understanding of local challenges and priorities. This should make organisations more efficient and effective, saving valuable resources such as money and time. We anticipate personal benefits for individual participants: confidence, empowerment, quality of life and sense of self-advocacy.

UfY's wide partnership activity with statutory sector organisations means that there are further opportunities to ensure lived experience can influence wider policy making and statutory service commissioning.

This project explores the engagement of people with lived experience in VCSE practice. This is necessary to allow UfY to achieve greater lived experience engagement in its activity, which should save resources via greater efficiency achieved through a better understanding of the needs of the community.

This project intends to enable UfY, and the VCSE sector it supports to enhance and develop existing lived experience engagement methods. The intention is to create a platform for meaningful engagement with people with lived experience which can be broadly replicated across the VCSE sector beyond UfY.

The project presented here is seeking to find ways of establishing on-going lived experience engagement which could clearly continue beyond the end of this project.

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2.The project's partnership methodology

When the project commenced in Autumn 2024, the first objective was to establish a group of UfY stakeholders willing to collaborate in this process. A social imagination workshop took place – an approach which supports participants to think creatively about a project. At the same time, CERT researchers conducted a literature review which took a broad approach to exploring coproduction and community engagement in VCSEs. The findings of this review were taken to the stakeholders for discussion. Two questionnaires were used to explore different aspects of lived experience engagement from the perspective of both UfY's Selby partners, and from the organisational perspective of the NAVCA (National Association for Voluntary and Community Action, the national membership body for local infrastructure organisations) respondents.

2.1 Up for Yorkshire stakeholders' group

A key achievement of this project has been the successful creation of a group of enthusiastic and highly engaged stakeholders from Selby (including UfY, VCSEs, local authority, and statutory health providers). Here, this project benefited considerably from the pre-existing positive relationships UfY already had with its community stakeholders, meaning the project could move fast as we did not need to spend much time relationship building as the relationships already existed. The project relationships were strengthened by the process of stakeholder steering groups, the social imagination workshop and literature review sense checking focus groups.

2.1.1 Establishing the stakeholder groups

The opportunity to join the stakeholder group was advertised broadly by UfY to its Selby partners. The group came together online for the first time in November 2024. At this meeting, the project was introduced, and we asked participants what they think 'works' in terms of lived experience engagement; what challenges we should be aware of as the research progresses; and what are the opportunities for change.

Key points identified in this first meeting include:

- Making sure we focus on issues that matter to people and that can be impacted by the engagement.
- Thinking outside the box - how can we do things differently/be more creative?
- The need to be really clear about scope of participation at the outset: ensuring it is relevant and the purpose is communicated clearly.
- Consider carefully why are we asking people to participate.
- Build capacity and skills of participants so that they become enablers and facilitators.
- Encourage funders to build this into the funded part of delivery. New processes/approaches should be embedded at the start of the project development phase.
- Making the participation engaging, inclusive and creative, offering different ways to be involved.
- Make it easy to participate – consider things such as meeting timings, work commitments and child care.
- Consider incentives for participation/paying people as equals.
- Skilled facilitation: trust, confidentiality, physical safety and psychological safety.
- Recognise power dynamics and really actively listening.
- Barriers identified included always having the 'usual suspects' at each meeting: sometimes it can be difficult getting new people involved and getting a varied demographic of people can be hard.
- Sometime times people will have a particular motivation for engagement that can distort/add bias to conversation.
- Apathy/engagement fatigue/low uptake should be considered, alongside an awareness that people with lived experience being fed up of being asked the same questions.
- The need to be brave and admit when things don't always go right - share things that have worked/haven't worked/best practice making engagement 'a bit better' is better than making no change at all, even if it's not 'gold standard'

This meeting was followed by a face-to-face workshop in Selby to which all participants were invited. The meeting addressed:

- How well do you think your group/organisation currently engages with people with lived experience?
- What do you see as the biggest benefit of engaging people with lived experience?
- How do you currently engagement those with lived experience?
- What works well?
- What are the challenges?
- What does success look like?

2.2 Social imagination workshop

Stakeholders were invited to a 'social imagination' workshop in Selby. This workshop provided participants with the opportunity to view their VCSE activity from a different perspective. 17 participants from the stakeholders' group took part. Participants of the social imagination workshop indicted a significant impact: they found the workshop to be particularly useful, especially relating to how they might communicate differently with those with lived experience that their organisation works with. Many attendees spoke of how attending the workshop will change their future practice.

2.3 Literature review

A literature review, which took a broad approach to exploring coproduction and community engagement in VCSEs, identified the benefits of lived experience engagement for service users; benefits for charities; and benefits for society. It also identified barriers which exist for VCSEs in attempting to engage lived experience in their practice.

2.4 Sense checking focus groups

Two focus groups, involving 16 participants from a range of UfY stakeholder groups, were held to 'sense check' the headline findings of the literature review, exploring and considering its application and impact on their own, and their organisation's daily activity/processes/understandings.

In the focus groups, in small groups of two or three, to stimulate conversations the participants were tasked with organising the headline findings in order of how they view their importance or relevance for VCSEs in terms of:

- Benefits for service users;
- Benefits for charities;
- Benefits for society; and
    - The barriers which exist to lived experience VCSE engagement.

This was done using slips of paper with each individual headline finding on. Participants were encouraged to move them around and reorder them as their discussions progressed. They were also encouraged to consider whether they could identify any factor that was missing from these categories.

Following this activity, the small groups shared what they had discussed with the whole group.

The quotations in this report are the written notes taken by a researcher of the whole-group discussions (rather than direct participant quotes).

2.5 Questionnaires

A questionnaire covering different aspects of lived experience engagement shared with UfY's local VCSE partners and achieved 35 responses (from roughly 150 organisations).

A questionnaire covering organisational aspects of lived experience engagement was shared with NAVCA (the national membership body for local infrastructure organisations) which achieved 8 responses (from roughly 200 organisations it was sent to).

The questionnaires have allowed us to understand different aspects of lived experience engagement from the perspective of both UfY's Selby partners, and from the organisational perspective of the NAVCA respondents.

3. What we learned about utilising lived experience

3.1 Literature review findings

Collaboration between health care, social services, and other sectors is increasingly seen as a route to improving health and health equity (Arnold, Coote, Harrison, Scurrah and Stephens 2018). Community engagement was seen as essential for building capacity and promoting social capital (Bagnall et al. 2020). Boosting social relations for community wellbeing means promoting those conditions in society that bring people together, enable them to participate in community life and allow them to feel part of a network of shared meanings (Bagnall et al. 2017). "Centring lived experience meaningfully like this is not a one-off exercise or something you can 'tick off' once you have completed. It's an ongoing change that often requires a significant cultural shift for a charity. It takes time, dedication and perseverance" (Lamb, Seifu and Chapman 2023, p5).

Community engagement is thought to improve health via its impact on the development and delivery of more appropriate and accessible interventions, as well as a direct positive impact on social cohesion and individual self-esteem and self-efficacy for those who are engaged. Recent work has indicated that community engagement interventions are effective in improving health behaviours, health consequences, participant self-efficacy and perceived social support for disadvantaged groups (Harden et al., 2015).

The literature review identified headline findings related to the benefits service users; charities; and society gain from engaging in VCSE activity; and also, the barriers which exist to lived experience VCSE engagement.

3.1.1 Benefits for service users

A range of benefits to service users from utilising their lived experience have been identified.

The possibility of finding meaning and purpose within their experiences has been raised as crucial: "this is especially pertinent for those who feel they have been written off by society, stigmatised, or lost years of their lives and have felt shame, pain, and distress" (Newton, 2022, p21).

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). This includes improved skills (Mind, 2025) and greater knowledge and opportunities (Newton, 2022). For some it enables them to carve out their vocation, and for others, it's about realising their worth and being able to achieve their hopes and dreams – Newton (2022) writes:

When you are part of an oppressed group of people, being part of a community that is trying to make a difference for themselves and others like them, gives people the strength to get up and do what they need to, or want to do. To tread this path on your own can be difficult, overwhelming, and exhausting, but to do it with others makes the challenge more manageable. The support that you give and receive from your peers is invaluable (Newton, 2022, p22).

Individuals realise that they have the potential to achieve their hopes and dreams (Newton, 2022). Feeling valued, empowered, respected, and worthwhile, means their self-confidence, self-esteem and wellbeing grows (Newton, 2022; Mind, 2025; Hatzidimitriadou et al., 2012; Pollard, Suddert and Tiratelli, 2021). This can be related to a sense of belonging and feeling understood, where people feel heard, listened to, valued, accepted for who they are (Newton, 2022; Hatzidimitriadou et al., 2012); and feel connected to their local community (Mind, 2025).

Parsfield et al., (2015) identifies a wellbeing dividend: here, those with lived experience feel part of the community; experience greater life satisfaction due to enhanced relationships; and social support protects them against harm to mental and physical health. Lived experience engagement can connect staff and volunteers more closely to the day to day experiences of people (Mind, 2025).

Peer support, friendship and solidarity are vital benefits for service users (Newton, 2022; Mind, 2025). Here, compassion, empathy, friendship, belonging, and an appreciation of others "happens when you are in spaces that enable you to learn from others who have been through, or are going through, similar life experiences" (Newton, 2022, p21). For some people, the support they gain from their peers leads to "genuine and authentic friendships" where they are

"more able to move away from people or parts of your life that have been unhelpful" (Newton, 2022, p21), for example, moving away from past friends who use substances.

Feelings of hope for the future and inspiration are important for service users (Newton, 2022). Seeing those who have gone before them and understanding their struggles with adversity and their achievements, can offer hope for a different future and inspiration that they too can achieve their goals. Tackling stigma, for example in mental illness, is also an important benefit (Hatzidimitriadou et al., 2012). Furthermore "what works for one person, is different for another, and hearing this can help you appreciate differences and try things that you might not have previously considered" (Newton, 2022, p22).

Lastly, lived experience engagement can be related to individuals becoming more trusting of services and can facilitate improved access of services, in particular, for minority groups (Hatzidimitriadou et al., 2012; Newton, 2022) and being better connected with services that meet their needs (Mind, 2025). Greater satisfaction with services and loyalty from service users has also been identified (Man et al., 2019).

3.1.1.1 Sense-checking discussion

Headline findings:

Meaning and purpose; empowerment; motivation; wellbeing; confidence; self-esteem; sense of belonging; feeling understood; peer support; hope; compassion; empathy; new knowledge and skills; more trust; and more appropriate services.

There were no particularly clear patterns across the different groups' organisation of the headline findings. For example, meaning and purpose and peer support were identified as most important for some groups and least important for others, perhaps suggesting a controversial element to some findings. However, such variation may be related to the challenge raised by some groups who found ranking the different headline findings difficult. This was because they felt that all of them were equally important. One group chose to put all the feelings together in one place because they felt that these were at the centre of it all and didn't feel like separate elements.

Motivation, confidence, hope and sense of belonging seemed to be viewed as generally important – and one participant observed that promoting lived experience brings a sense of belonging and interest for people. More appropriate services were raised by one group which observed that if you don't get the lived experience engagement right, people feel let down, meaning you can't get all of the positive things from engaging lived experience.

Wellbeing appears to be generally lower down the list of importance, with one participant cautioning that wellbeing can be read as either positive or negative. This means the process can sometimes harm wellbeing if it is not done right.

Some participants talked about new knowledge and skills with one explaining how engaging brings positive things which leads to practical improvements. This process can yield some longer-term characteristics in an individual, e.g., helping them to engage with life. This may lead to a positive spiralling upwards motion for that individual. Furthermore, one participant described how lived experience work can be a catalyst for many positive things for individuals.

Empowerment was also the subject of group discussion. One group observed that this can be a journey: people need the sense of being understood, empathy and compassion. This is away of drawing someone into the project, which then hopefully improves their confidence. They observed this put individuals in places in which they can find skills which lead to better wellbeing.

In terms of feeling understood, participants commented that the power of being listened to should not be underestimated. One group put trust and confidence at the top because they felt that without these 'you can't get anywhere'.

Another group expressed the idea that everyone has something to bring to the table. They observed that where you don't feel like someone understands you, you won't trust them or engage. They described how the whole demeanour and attitude of someone changes when they know that they are understood, and that this leads to all the other good stuff from engagement.

Another group rated feeling understood as most important. For them the 'end game' is that the services we provide speak to the people we support. They highlighted the idea that spending time to speak with people allows you to fully understand who they are.

One group highlighted the importance of empathy and compassion to relating with people. One gave an example of disengaging with a service which made them feel worse – people need someone who actually understands them and encourages their wellbeing. A sense of belonging brings people back into society, and makes them more involved. Again, they observed that clients need a holistic approach to engagement.

3.1.1.2 Missing factors

The groups were asked if they thought anything was missing from the findings of the literature review in the category of benefits for service users. One group suggested that 'agency' is possibly missing, although they recognised that this is close to empowerment. They suggested the difference might be that empowerment sounds like giving an opportunity, but agency is taking control of something. However, another group member suggested that the term 'agency' is potentially confusing, because they use the word 'agency' but in a different way (e.g., working with different agencies).

Lastly, one group raised that 'having a voice' is missing. For them, having a voice means being listened to, and that your thoughts and ideas will be implemented in the service.

3.1.2 Benefits for charities

Newton (2022) discusses at length the benefits charities gain from lived experience engagement. For them, people with lived experience bring authenticity to the charity's work. Their personal stories and insights can build trust with beneficiaries, funders, and the public (Newton, 2024). For some charities, lived experience engagement offers them a reason for existing or surviving; allowing them to do what is needed in the community (Newton, 2022). Newton explains that organisations founded on lived experience have this "so deeply woven into the fabric of their existence, that they cannot do what they do without it" (p23). "Without seeking out the opinions, ideas, and experiences of people with lived experience, you can't possibly know that what you're doing is truly needed and wanted, or what works and what doesn't, or what helps and what harms" (p23). Furthermore, Newton (2024) cites long-term sustainability and resilience as direct benefits of lived experience engagement.

The importance of mutual learning (Hatzidimitriadou et al., 2012); improved access to information (Man et al., 2019); stronger support for innovation and change (Man et al., 2019); and greater knowledge and expertise on a particular issue (Man et al., 2019) are highlighted as key benefits for charities. Lastly, stronger relationships were identified as important by Hatzidimitriadou et al., (2012) and Man et al., (2019), including stronger leadership and convening skills (Man et al., 2019).

Greater involvement with and learning from communities are identified as considerable benefits (Hatzidimitriadou et al., 2012; Newton, 2024; Parsfield et al. 2015). Here, individuals with lived experience have deep connections within their communities. Charities can then utilise these connections to reach and engage with hard-to-reach populations more effectively (Newton, 2024). Thus, integrating people with lived experience can "foster a more inclusive environment, promoting diversity in thought and approach" and this diversity enriches the charity's culture and operational effectiveness (Newton, 2024). Lastly, Newton (2024) observes that "programmes co-designed with those who have lived experience are more likely to be sustainable in the long run, as they are better aligned with the actual needs and realities of the communities served".

Newton (2024) identified that lived experience provides valuable perspectives that can inform a charity's strategies, ensuring that programmes and services are relevant and effective. This leads to better-targeted interventions that truly address the needs of the community. Here, involving individuals with lived experience can help build resilience. As these individuals take on active roles, they become leaders and role models, inspiring others and fostering a supportive network (Newton, 2024).

Another key benefit for charities is simple but smart solutions to complex problems. Newton (2022) explains that people with lived experience "often have amazing problem-solving skills that they have developed over their lifetime and use their imaginations to create better futures" (p23). Newton explains that when these skills in this are sought, "what is often elusive to those working within the sector or becomes too complicated to implement, suddenly becomes more obvious" (p23). This allows organisations to completely change how they work for the benefit of the people they serve, sometimes introducing radical new ways of working, which can be more cost-effective and more popular.

Thus, lived experience can lead to more innovative and practical solutions leading to improved service design and delivery. Lived experience feedback can help design programs that are user-friendly and address real-world challenges (Newton, 2024). Furthermore, Newton (2022) identifies that when service uptake is high, it "can demonstrate a level of need that potentially opens up more funding opportunities" (p23).

Often, people who have previously accessed their services

want to give something back. When this happens, it can create a pipeline of volunteers and/or staff who know the organisation well and want to contribute to what they do so that it benefits others who are in receipt of their services (Newton, 2022). This can lead directly to more empowerment and advocacy: engaging people with lived experience empowers them and offers a platform to share their stories and advocate for change. This can influence public opinion and policy, driving systemic improvements (Newton, 2024). Further benefits from lived experience engagement include workforce improvements (Newton, 2022); a shift of professional attitudes; and financial gains (Hatzidimitriadou et al., 2012), for example, cheaper development costs (Man et al., 2019). More credibility with funders and the public has been identified (e.g. Mind, 2025; Newton 2024; Newton 2022). Newton explains how:

You're more likely to accurately represent the people that you serve when you're in direct contact with them, rather than relying on other people telling you what their lives are like. This can help avoid reputational damage that can be caused through inaccurate portrayals, particularly when it comes to marketing, campaigns, and external communications (Newton, 2022, p23).

In addition, including people with lived experience can help ensure a more ethical and rights-based way of working that does things with people rather than to them or for them:

It challenges people's assumptions about other people that is often based on ignorance or a false 'them and us' division. It can also prompt people to consider their broader learning and development needs, brings more challenge to their work and enables the workforce to work in anti-oppressive ways (Newton, 2022, p24).

In this context, hearing first hand stories from those who have benefited from the charity's work can be highly motivating for staff and volunteers. It offers a tangible and rewarding sense of the impact of their efforts (Newton, 2024).

The provision of culturally appropriate services (Hatzidimitriadou et al., 2012); greater inclusivity and diversity (Newton 2024); and improved access and inclusion have been identified as key benefits from lived experience engagement (Newton, 2022). When services are designed by people who often find themselves intentionally or unintentionally excluded from mainstream society and services, they are naturally more accessible to their peers (Newton, 2022).

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). Related to decision making is increased accountability and transparency. Here, involving people with lived experience in governance and decision-making processes can enhance the charity's accountability. This ensures that the organization remains true to its mission and responsive to the needs of those it serves (Newton, 2024).

3.1.2.1 Sense checking discussion

Headline findings:

A reason for existing; smart solutions to problems; shift in professional attitudes; improved service design and delivery; workforce improvements; better accountability and transparency; cheaper development costs; more credibility; more culturally appropriate; greater inclusivity and diversity; enhanced motivation; expertise on specific issues.

In the group discussions, expertise on specific issues was highly rated by several groups, alongside improved service design as a rationale for engaging lived experience. Several groups discussed accountability and transparency, with one expressing that this is the most important factor. One felt that by virtue of involving a lived experience voice, governance and accountability, etc., should increase. Workforce improvements seem to be ranked in the middle by many groups.

Some groups raised more culturally appropriate services as important, while other groups rated this headline finding lower down. This may suggest an element of controversy or differences in the goals or focus of the different organisations in the room – e.g., those that work with asylum seekers may view the need for culturally appropriate services in a different way.

Similarly, inclusivity and diversity were often ranked as either most important or least important by the groups, again perhaps suggesting that it may also be a controversial issue or a consequence of different organisational focuses as before.

Expertise on specific issues was discussed in detail by the group. For one group, expertise and lived experience make the organisation more credible. Another group reflected on how lived experience input brings expertise on specific issues. A different group observed that the more people you talk to, the more diverse the solution will be. However, one group cautioned that it is important that this makes the assumption that everyone you are talking to knows the solution they need. They explained that this means the timing of the thing, the intervention, is as important as the intervention itself.

Another group observed that lived experience is a very personal thing: you can't assume that the same thing is always helpful for everyone. This means that lived experience has to be really well managed because it's so individual. They warn against pushing one individual's lived experience onto everybody else. This reflects the danger of assuming that all service users are homogenous in terms of their needs and skills. Another group extended this, explaining that when an organisation claims to be the voice of something (where you might have collected a lot of voices), it might be that only the loudest voices are heard. They questioned how to ensure that you get a fair and representative perspective. This reflects the perpetual challenge of the same group of service users engaging each time, missing the input of the large group of individuals who never come forwards.

Cheaper development costs and a reason for existing were controversial, with some groups rating them as most important, but others emphatically rejecting them. For example, one group argued that lived experience engagement is definitely not cheap in terms of time, money, energy, promotion, etc.

One group put reason for existing first. They explained that as a volunteer, they felt it was really important to them: it is why they volunteer and donate. However, another group member counters this reading of the card: they read it from the narrow point of view of what it brings to a charity. For them, lived experience isn't a reason for existing, instead they expressed that they are there to exist until there's no reason for them to exist anymore. Another group member suggests that lived experience reinforces the motivation to exist. They suggested that if you add 'reinforce' to the card it goes to the top of their list. One group placed reason for existing with enhanced motivation viewing it as a motivator.

Several groups discussed the role of a shift in professional attitudes. For example, one group observed that it depends on where that organisation is at and how honest it is at reflecting on itself. They highlighted that a high level of self-awareness is important here. Another group commented that the shift in attitudes depends on where you started. For some organisations it can be a dramatic change. This includes people with lived experience groups being paid salaries.

Enhanced motivation was also discussed by groups – the motivation of service users to give something back: one group observed that the best volunteers are those with lived experience.

Improved service design and delivery was raised in terms of decisions being made which take lived experience into account. This is not a reason for being for a charity, but perhaps a reason why a project exists. One group expressed that lived experience can be seen as a massive learning experience. They explained that you can think you are doing the right thing but then find out that you aren't. They argued that lived experience groups can also provide the organisation with accountability: the lived experience group will follow up and ask for answers if you don't follow up on things. This offers a different perspective on accountability and transparency.

3.1.2.2 Missing factors

In terms of factors missing from the highlights, one group observed that *communication* and *networking* are important. For another group *evidence based* is also missing. For them, you have to demonstrate that what you're proposing is valid, value for money, etc. *Legitimacy* was raised by one group, who explained how:

- Lived experience work can give gravitas and greater legitimacy;
- It can enable funding to do more (funders love it!);
- It can build trust far quicker with target audience (sometimes need to engage trust quickly. If lived experience group say yes others can follow);
- It can get you greater access to decision makers (e.g. emotional response by decision makers from hearing someone's story).

The group member noted that they didn't mean this manipulatively – they explained that they will always tell people about this and the need to share their stories with those in power.

3.1.3 Benefits for society

Benefits to society from lived experience engagement includes a contribution to broader social change. Lived experience engagement enables society to challenge the social systems, structures, and narratives that define people (Newton, 2022). This leads to the development of solutions to some of the most complex issues in society through changes to national policy based on people's lived experiences (Newton, 2022). Community power can strengthen community wellbeing and resilience (Pollard et al., 2021).

This can include enhanced democratic participation and social trust and improved community wellbeing, resilience and cohesion (Pollard et al., 2021) which combats stigma and discrimination. Newton (2022) observes that:

the more people that do this work, the more that taboo, sensitive, or challenging life experiences can become normalised within society. When people share their experiences of issues such as domestic abuse, homelessness, addiction to drugs or alcohol, or mental health issues, it challenges the general public's assumptions about what people look like, sound like, and behave like (Newton, 2022, p25).

Newton (2022) explains that lived experience work challenges people about their privilege, power and position in society. This lived experience work creates a more inclusive and anti-oppressive society, where more and more people are beginning to question their position in the world and how everyone is complicit within systems that oppress people.

Parsfield et al. (2015) write of a citizenship dividend: a greater sense of empowerment; more skills and access to work or education; and collective agency – cooperating to get things done in society (latent power within local communities. Similarly, Pollard et al., (2021) explain how lived experience engagement embeds prevention and early intervention in public services.

Furthermore, Parsfield et al. (2015) highlights an economic dividend from lived experience engagement: increased participation in work, training and volunteering; increased resilience and viability of community services; and notional savings to public budgets through preventative demand management (saving money).

Lastly, Hatzidimitriadou et al., (2012) observes the importance of building the capacity of communities to deliver public health services (Hatzidimitriadou et al., 2012). Similarly, Parsfield et al. (2015) writes of a capacity dividend from lived experience engagement: benefits spread through networks rather than just helping individuals; influential change-makers can be identified to target greater returns on investment more efficiently; highly connected individuals contribute to greater community capital – and benefit in turn from that increased capital.

3.1.3.1 Sense checking discussion

Headline findings:

Social change; reduced stigma and discrimination; improved community cohesion, resilience and wellbeing; enhanced democratic participation and trust; citizenship dividend; economic dividend; improved access to services and greater community capacity.

The groups noted that this was a much quicker exercise than the previous two tasks, but some groups reported finding these cards difficult to rank.

Interestingly, improved community cohesion and resilience and wellbeing were top for everyone. Improved access to services is high for most, with one group explaining that there is a potential loop here: there is no social change (or other things) without proper access to services.

Reduced stigma and discrimination alongside social change were also high for most groups. Some groups viewed social change as woven throughout as the result of good things happening. One group expressed that people might assume social change is a good thing – but actually it can go either way. For them, crucially, social change can only happen if there's somewhere to go and if you have a voice.

Enhanced democratic participation and trust led to mixed rankings (top or middle). One participant observed that there were too many long words in that! They commented that while they understood the concept, they did not understand why 'democratic' was in there.

Greater understanding was also raised as important. One group observed that the thing that alienates people and creates tribalism is the lack of understanding. For them, the democratisation of services means that where somebody else's need is greater than yours, it's fair that resources are diverted to meet their need rather than yours. Another group explained the importance of knowing and understanding your target your audience.

Another group raised a concern about 'the individual' getting lost in discussions around society. For them, governments are looking at big picture, assuming 'service users' are homogenous groups rather than considering individual differences.

One group highlighted the need to use the language and buzzwords which funders are looking for when applying for grants (e.g., 'coproduction'; 'impact'; 'collaboration' and 'partnership').

For one group greater understanding is related to language. They observe that language can alienate. If someone sees a hidden agenda or doesn't understand the language, etc. can lead to questions about the specific agenda at play. They commented: is it that that you want money from me, or you want me to vote for you?

Improved access to services for service users for support was discussed and compared by one group to the better services card from the benefits to service users' section. This suggests that lived experience engagement can lead to individuals receiving improved access to manifestly better services.

A key observation for this category is that some groups didn't know what to do with citizen and economic dividend. They struggled to understand the concepts and did not like the language. One group asked for clarity about what was meant by citizenship dividend? Another group described how of people are feeling financially okay, a lot of the difficult, horrible, fragmented 'stuff' is lost. For them, this is a big part of trusting in that bigger system. They warn against idea of the political mandate as only representing certain people. Furthermore, they cautioned that social change can be good but it can also be bad. One group observed that reducing inequalities in society is missing, but this may be viewed as an element of the citizenship dividend.

3.1.3.2 Missing factors

Some ideas raised as being missing here included *managing expectations* – being realistic what you can actually achieve with lived experience voice; and *different priorities* – one group highlighted that some people advocate for the 'bee in their bonnet'. They identified the need to look at the 'collective good' instead. Another group suggested that the idea that people having more of a voice can cause problems, for example, when people want to be in a particular position of power, or when they are awkward/difficult to work with.

3.1.4 Barriers to utilising lived experience engagement

Coproduction done badly may cause more harm than good (Newton, 2022). There may be a lack of commitment or reluctance to engage fully from both charities and the people with lived experience they want to work with (Hatzidimitriadou et al., 2012; Bagnall, South, Jones and Southby, 2024). Coproduction challenges people and previous 'bad' experiences can linger (Newton, 2022). Management of expectations for all parties is important (Hatzidimitriadou et al., 2012). People can get stuck (both professionals and service users), preventing change (Newton, 2022) and taking risks challenges everyone (Newton, 2022). A lack of inclusive and accessible practice within the organisation is a significant barrier (Harden et al., 2015; Newton, 2022). Man et al., (2019) identified the need to make engagement safe and inclusive – equipping everyone with the skills to participate or facilitate fully is vital.

A problematic organisational culture poses significant challenges for lived experience engagement. This includes the quality of pre-existing relationships between communities and the charity; attitudes; practice; and habits around working inclusively (Newton 2022). Tendencies around risk taking can present a challenge (Newton, 2022). Curvers et al., (2016) observes that when user feedback is negative—as it frequently is—this can be daunting for the charity's staff. Here, staff may feel that their professional experience and capabilities are being personally challenged or attacked, or that negative feedback is a risk to the wider organisation. Thus, finding the right individuals to do the work is important (Curvers et al., 2016). Developing a safe feedback culture requires effort, preparation and intentional cultivation (Curvers et al., 2016). Here, creating a socially safe team means people can admit when things go wrong without fear of serious adverse consequences for them. Differences in organisational culture, attitudes, and practices between participating organisations can also pose potential difficulties in multisector collaborations (Bagnall et al., 2024). Changing culture is hard, takes time and can be challenging (Harden, Sheridan, McKeown, Dan-Ogosi and Bagnall 2015).

Power is a significant component which relates to organisational culture. Differences in decision-making processes; competition for power and resources; and lack of accountability between agencies were identified as barriers to collaboration (Arnold, Coote, Harrison, Scurrah and Stephens 2018). Senior leaders play a key role in shaping how local collaborations and their governance functioned—for better or worse (Harden et al., 2015). This may include conflicting agendas and issues of power such as resistance to sharing power and control (Hatzidimitriadou et al., 2012; Bagnall et al, 2024). For approaches to user voice that devolve operational decision-making to service users, it is crucial that management and charity trustees are prepared for the shifts in power away from them to their service users (Curvers et al., 2016). Putting unnecessary requirements on job role descriptions that limit who can take part is another barrier (Man et al., 2019).

Governance structures within the organisation may harbour strongly held professional beliefs about what is best for the community and there may be staff unease about adopting a different approach (Bagnall et al., 2024). Shared processes and systems—such as agreements for sharing information, joint meetings, and planning processes support organizations to communicate and work together (Arnold et al., 2018). This work may be hampered by limited capacity of community organisations and by limited skills of professionals (Hatzidimitriadou et al., 2012) – finding the right people to do the work is important (Newton, 2022).

Cost is a significant challenge (Curvers et al., 2016). For example, costs arising from the extra time needed to work collaboratively, resources for paying lived experience partners, funding travel expenses and childcare costs (Bagnall, South, Jones and Southby (2024). On the other hand, staff may be working unpaid overtime due to the burden of the project (Bagnall et al., 2020), perhaps leading to burnout (Harden et al. 2015).

Practical challenges relate to the logistics and costs of getting people to provide feedback, and in ensuring that users' voices are not drowned out by the most vocal users, (senior) staff or the governing body (Curvers et al., 2016). Because of the time required and the dependency on certain individuals with key skills, there are dangers of both 'burn-out' and difficulties of succession with staff changes (Bagnall et al., 2020). Organizational collaborations depended on having sufficient resources to fund and deliver interventions (Harden et al., 2015).

Time and flexibility are another considerable challenge, it can be difficult to see the difference it makes especially at the beginning when the benefits have not yet been demonstrated (Curvers et al 2016; Man et al, 2019; Newton 2022). Once feedback is flowing there is an imperative to respond, and this requires flexibility (Curvers et al., 2016). A further danger arises from where individuals overidentify with the organisation and feel that their way of doing things is the only way, acting inflexibly (Bagnall et al. 2020).

Another challenge raised by Curvers et al., (2016) is that frequently, charities just do not know how to cultivate user voice. They may work with individuals who are hard to reach and difficult to gather feedback from. There can also be practical challenges in the logistics and costs of getting people to provide feedback. Ensuring that users' voices are not drowned out by the most vocal users, (senior) staff or the governing body is another challenge. Poor quality relationships with communities may hamper progress (Harden et al., 2015). Lastly, there are technical challenges in analysing, visualising and investigating feedback data (Curvers et al., 2016).

Other challenges relate to technical problems in analysing, visualising and investigating feedback data (Curvers et al., 2016); and in infrastructure: investing in infrastructure and planning; support, training and capacity building (Harden et al., 2015). The ability of organizations to collaborate was shaped, in part, by the infrastructure in place between them (Harden et al., 2015). Earlier on in a project, it can be difficult to see the difference it makes (Newton 2022), which can be demotivating for all parties.

3.1.4.1 Sense checking discussion

Headline findings:

Done badly it can cause harm; problematic organisational culture and governance (resistance to power sharing, lack of commitment; lack of skills; conflicting agendas, risk taking and attitudes); infrastructure and technical problems; management of expectations; logistical problems (costs and other practical problems); only hearing the most vocal (missing the harder to reach); poor quality community relationships; costs (travel expenses, childcare).

One group expressed that they would be hard pressed to say that you'd find someone who didn't want to include lived experience. Here, barriers may be more generally seen as being about the how and not a lack of desire to do it.

Done badly it can do harm was rated as of high importance by almost all groups. Here, one group observed that done badly causes harm may be used as an excuse for not attempting to engage lived experience in the first place. Another group noted that while this is an important issue, they suspected that this reason wasn't why organisations don't do it. They suggested that there were more practical barriers to lived experience engagement. Related to this, one group highlighted that people tend to stop doing things if they don't think they can do them well. This leads to a barrier - the feeling that if you can't do something fully – a 'gold-plated' engagement, then you won't do it at all. This suggests that perfectionism has the potential to be a significant barrier through preventing organisations from making small changes towards lived experience engagement.

Management of expectations was rated as of very high importance by most groups, who felt that high (unattainable) expectations of all involved about what a given project could achieve could be a barrier and a significant source of dissatisfaction. The ordering of the rest of the headline findings was quite varied.

One participant described terrible examples of lived experience work. For them groups that promise everything are patronising. And also, claiming to do everything is a lie because no one can achieve everything in reality. Related to this is whether those with lived experience really believe they can effect positive change: if they don't believe that they can achieve change, they simply won't engage with the project.

One group explained how real barriers to engagement relate to making lived experience engagement feel dull, wordy and boring. They argued that you have to make things fun and interesting for participants.

Another group explained that it's not always easy to manage volunteers in the first place, but adding lived experience volunteers with complex needs can make managing volunteers even harder. They explain the need for 'juggling' the needs of volunteers, attendees and the funding. One group suggested that a further barrier could be the need for 'appropriate opportunities' for the group in question. For example, those with long term chronic health needs might prefer a drop-in coffee morning rather than other means/types of engagement.

There was considerable group discussion about only hearing the most vocal (missing the harder to reach) being a significant barrier. This is related to the challenge of the same people coming forward each time, missing those people, who for whatever reason, never come forward to engage. However, one group raised that this is just poor facilitation – you should get someone who's better at it. Only hearing the most vocal is arguably related to the barrier of poor-quality community relationships. One group raised the importance of getting the 'right people' with the right relationships to groups to deliver the lived experience engagement.

Infrastructure and technical problems were discussed, including issues about data sharing and computer systems. Costs were also considered to be of high importance. Another key infrastructure and cost concern raised by one group is transport – particularly in rural parts of North Yorkshire – this is a genuine barrier to engaging the community. One group noted the need for funding to make resources accessible (e.g. easy read resources, translators). Another commented that cost barriers could be overcome, but people don't always ask for the support they need. One group emphasised that engagement must be properly resourced.

Organisational culture and governance were discussed by one group, who suggested that organisations need to 'hold a mirror up to themselves' and see if they have a problem. Problematic organisational culture was raised – with one group suggesting that this is a question of resources. They explain that this can be a particular challenge for VCSEs which are heavily reliant on volunteers. It was also observed that sometimes it is perceived that there are too many legislative 'hoops to jump through'.

3.1.4.2 Missing factors

One participant felt that there were a lot of things missing here, particularly related to barriers to organisations generally, for example: the assumption that it was not needed; staff skills; capacity; competence; funding/funded time; and uncertainty if the value of the work will be recognised by partners and others.

Time was also added by participants. One group argued that the biggest reason people do not do lived experience work is that they don't have time, they think they don't have the time, or they don't value it enough to make the time.

In addition, a further barrier, communication, was added by participants. One group explained that for participants need to consider whether it is the 'right opportunity for me?' Organisations need to carefully consider how they explain the engagement opportunity to those they are seeking to engage, especially where there are different levels of lived experience involvement for participants. This group suggested that 'giving it a fancy name' can be a barrier because people will simply not understand what it means or what they might expect should they choose to engage in the VCSE activity.

Related to risk of doing harm, the risk of trauma to individuals associated with sharing their lived experience was identified as being missing. For example, it was raised that expecting people to bring their personal history with them to meetings etc. can be asking a lot of them. One group emphasised the danger of retraumatising people with lived experience. Another participant agrees with this, explaining that their organisation uses trauma informed practice where there is no judgement and offers a quiet trauma informed space for people to go at their service. Other participants supported the importance of this and the need for a safe space where people can go.

3.1.5 Ways forward from the literature review

Focus group participants were asked for ideas about the ways forward for VCSEs in engaging lived experience in their activities. They highlighted that often, VCSEs need help to implement lived experience engagement.

Sufficient funding/resources was raised as a fundamental and necessary component. It was noted that some activity needs to be government-led, an example given by a participant was the government drive to get people off sickness benefits and back into work had been passed onto VCSEs. They expressed concern over the assumption by government that the VCSE sector will pick this up without giving any additional funding. Sufficient grass roots funding was identified as critical for putting VCSEs in a position where they can offer meaningful volunteering, work experience and other opportunities (in particular for small VCSEs).

Another key point raised here was the management of expectations among the different stakeholders involved in projects. Some focus group participants raised the importance and need for stating clear boundaries and guidelines for lived experience activities – VCSEs must make sure volunteers and other participants understand these boundaries. The knowledge, skills and commitment to see things through was also identified by participants as crucial.

One participant raised language as important to lived experience engagement, in particular, that it should create a 'level playing field'. They suggested the need for a change in language – no more 'service users', 'clients' or 'cases' which are often thought of as potentially stigmatising, although they did not suggest an alternative term.

Another participant observed that how to plan, design and implement activities needs to be carefully considered. The process needs to be accessible for those with different needs, for example, physical access, written materials, understanding terminology and remote working (e.g., access to laptop/tablet/phone etc).

There is also a need to consider at the beginning who is right person to involve in different aspects of the project was also raised. The right person can be key, and if they leave the organisation, a whole scheme of work may no longer exist. The need to capture the 'essence of a person' so others can continue to do what they do to continue a project was highlighted by one focus group participant.

It was also identified that individual supervision and mentoring for individuals with lived experience is often needed. One focus group participant identified that learning together is important, for them, that's how lived experience engagement actually could be made to work in reality. However, they cautioned of the "need to look outside our own box" for ideas about planning, designing and implementing lived experience. For them, there is a need for reflection by both organisations and the lived experience individuals they engage with for improvement to take place.

Trying to encourage organisations to feel comfortable with what they reasonably can do is necessary. A 'ladder' model with different levels of lived experience engagement was suggested to take pressure off of organisations so that they don't feel they have to do everything from the beginning. This can be directly related to Sherry Arnstein's 'Ladder of Citizen Participation' (Arnstein, 1969). This views citizen engagement as rising up or down a ladder. It moves from non-participation (manipulation and therapy); to degrees of tokenism/ 'counterfeit power' (informing, consultation and placation); through to degrees of citizen power (partnership, delegated power, with citizen control at the top). Organisations may be able to use this ladder to help them consider where their different activities are positioned and whether it is desirable to move up or down the ladder according to the specific needs of that activity. VCSEs should be reassured that it is not essential (or realistic) that everything they do should always be at the top of the ladder 'citizen controlled'.

Another crucial point raised by participants was the need to demonstrate the worth of lived experience engagement via comprehensive evaluation. Justification for the lived experience engagement approach and evidence for impact is required to ensure it can continue in future. This evaluation process should be planned during the initial design stages, moving onwards through the project. Evaluation methodologies should always be inclusive, perhaps using creative approaches.

Another participant stated the need for VCSEs to be accountable, have open feedback and speak up and having an organisational culture in which people feel safe to discuss what happened when things go wrong.

A further focus group observation was the importance of education and training for people with lived experience to allow them to participant meaningfully. This is needed from the beginning to enable sharing and to be open to different suggestions/ways of doing things. One participant suggested using SMART goals (goals which are specific; measurable; achievable; relevant; and time-bound) to practice involvement and to evaluate involvement and enabling sharing.

In terms of interactions with other organisations relating to lived experience engagement, it was observed that sharing information needs to be at the forefront – identifying and sharing what best practice looks like. There was a suggestion that a buddy system between different VCSEs and service user forums could be of use here. An organisation directory was also suggested to allow VCSEs to find and communicate with each other. These approaches could be used as a way to start valuable conversations between organisations.

Case studies and tool kits were a popular suggestion by/ request from focus group participants, in particular, 'what worked' and 'how they did it', including, for example, tool kits covering:

- Hints and tips on how to use lived experience successfully;
- Flow charts of guidance for implementing trauma informed practice;
- Flow charts of guidance for building funding bids;
- Templates of lived experience policies in organisations;
- Governance templates;
- Surveys for evaluation.

4. Questionnaire findings

4.1 UfY VCSE questionnaire

A questionnaire was circulated with UfY's VCSE partners. It covered:

- What does 'lived experience engagement' means to you?
- How important is lived experience engagement to your work? Why do you think that?
- How good do you think your organisation currently is at engaging lived experience? Why do you think that?
- What you do right now that works?
- What have you tried that didn't work?
- Do you want support with your lived experience engagement?

Out of the roughly 150 organisations the questionnaire was shared with, 32 complete responses were received. The majority were registered charities (15); five were Community Interest Companies/Organisations (CIC/CIO); and five were Local Authority.

Figure 1 indicates that most respondents reported having primarily a Health and Wellbeing focus (13) or a Community Support focus (10).

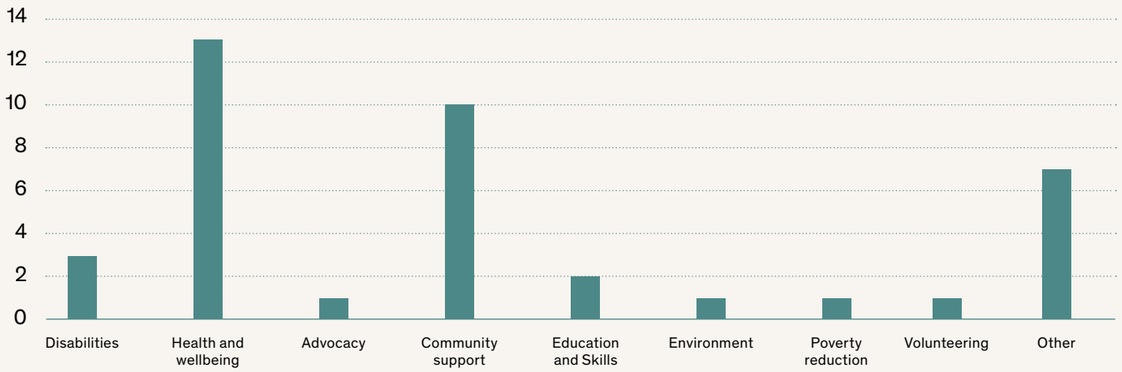


Figure 1: Organisation focus

Highlighting the importance of lived experience engagement, respondents explain that:

It's incredibly valuable when done right, but it's easy to pay lip-service without real engagement. Perceived barriers are resources and time needed [Health and Wellbeing].

Lived experience engagement is vital to services, as it helps you to deal with facts rather than assumptions, many of which will be very close to reality, but often things will get missed [Disabilities].

One respondent offered a caution about lived experience engagement:

We also understand that people with mental illness are not a "group" or a "community." They are individuals and we need to reach a wide range in order to then find points of commonality upon which we can base our services and strategy [Health and Wellbeing].

4.1.1 What does 'lived experience engagement' mean to you?

A range of views and definitions of 'lived experience' were offered by respondents, these include, for example:

> 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].
>
> It means actually speaking to or involving the people who have lived through or are living with the experience that you are seeking to support [Community Support].
>
> Actively listening and proactively responding. Creating opportunity for meaningful inclusion of lived experience voice [Domestic Abuse After-Crisis Support].
>
> Being able to relate to and empathise with individuals who may be struggling for whatever reason [Community Support].
>
> It means listening properly to the people we have any kind of relationship with. Understanding their life experiences what they have experience throughout their life. How it's affected them [Health and Wellbeing].

Organisations benefiting from lived experience insight was raised:

> Inviting people with lived experience of an issue or situation or challenge to join in a conversation/build a relationship with us as a local authority (or more probably part of a local authority) so that we can benefit from their insight. Can be at different depths but the ultimate would generally be seen as coproducing a solution to a "problem" or jointly designing a service to better meet resident need [Community Support].

For some respondents, 'lived experience engagement' captures involving those with lived experience in the development and delivery of the service in a way which is experienced by participants as meaningful and empowering, beyond just 'listening' to them:

> Involving potential and current beneficiaries of your service in the review of, definition, development and delivery of those services [Health and Wellbeing].
>
> 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].
>
> Involving people who have lived experience of accessing support or services in our work, whether it's from informing, right through to coproduction and codesign. It means doing this in a meaningful and empowering way and valuing their experiences [Health and Wellbeing].

Respondents highlighted the importance that lived experience is engaged throughout a project, not just a one-off exercise:

> Lived experience engagement, to me means involving those with lived experience of a particular topic to shape the work we do, and keeping those people involved throughout a project and beyond, not just a one off conversation [Disabilities].

Other respondents considered the need to work directly with different groups:

> Lived experience engagement to me means working directly with different groups of people or individuals, listening to their experiences and opinions, and taking from that what we can do to better support them rather than making assumptions [Statutory Service].

A sense of activeness was explored by some respondents:

> "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].

One respondent explained that lived experience should influence policy, with a need for significant engagement. They gave the example of not assuming everyone with mental illness has the same need.

> 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. Particularly when it comes to health, we cannot assume there is commonality of need between all people who live with mental illness for example [Health and Wellbeing].

One respondent highlighted the idea that lived experience brings insight that we cannot get from papers, contracts or policy guidelines:

> I believe lived experience in healthcare means valuing and listening to the real experiences of people who are navigating the complex health and social care system whether that be as patients, carers or family members. It's not about theory, statutory obligation or policy, but about how healthcare feels, works and impacts people (both positively and negatively). People and their lived experience brings insight that we do not get from papers, contracts or policy guidelines. The real patient voices should be at the centre of shaping what we do and plan- ideally there to help improve patient care and with a long term goal of helping our SHARED system become more compassionate and effective [Health and Wellbeing].

4.1.2 How important is lived experience engagement to your work?

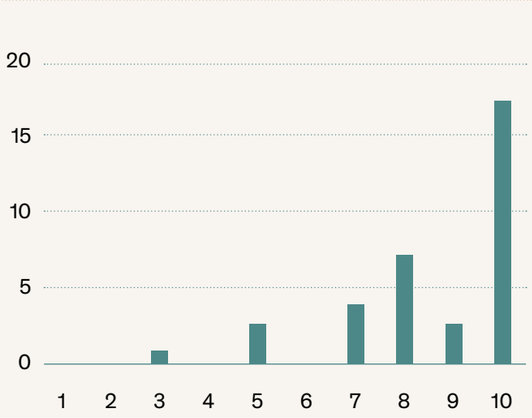


Figure 2: How important is lived experience engagement to your work? (10 is 'extremely important')

17 respondents answered that lived experience engagement was at 10, the maximum option (figure 2). Reasons why it is so important include:

> It is essential to have the input to ensure services remain relevant and inclusive [Community Support].
>
> We are an organisation specifically run by and for people with a specific life experience [Health and Wellbeing].
>
> Without involving people, how do we know what their needs are, thus leading to pointless interventions and funding spent incorrectly [Health and Wellbeing].
>
> An equitable society benefits everyone this can only happen if everyone is valued and minority groups are catered for and that means finding out about their needs from their perspective and lived experience [Health and Wellbeing].
>
> Because it is the best way of knowing that you're actually being effective and responsive to people's needs [Health and Wellbeing].
>
> We cannot achieve our aims of ACTION and ADVOCACY without our aim of AWARENESS [Volunteering].

The need for knowledge about precisely which barriers their clients face/their actual needs was highlighted:

> It is extremely important to our work, as we could not possibly talk about barriers to people with disabilities without knowing exactly what those barriers are, anyone could have a guess, but in order to get it right we must involve those living it on a daily basis [Disabilities].
>
> Without listening and working with people with lived experience we wouldn't be able to provide opportunities based on people's needs, address stark inequalities or attract the people we want to support to our groups [Health and Wellbeing].
>
> 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].
>
> Because what people genuinely need (rather than what is easy for us to deliver) should be at the heart of the work we do. Change is only possible when people buy in to what you are trying to do and we need people with mental illness to see our services as designed and appropriate for them, led by them and evaluated by them. Otherwise, we are imposing our own view onto what people need (as is usually the case in commissioning.) [Health and Wellbeing].
>
> 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 [Other, unspecified].

Respondents also highlighted that lived experience saves on resources and offers better care/support for people:

> Because people with lived experience have so much to offer which can improve our work through service design, saving on resources and ultimately offering better care for people [Health and Wellbeing].

> The families we support react better when they know their volunteer supporter can really relate to what they are experiencing/struggling with/going through. The families, of their volunteer supporters, say things like "they really helped, because they "got me" "She understood" "she didn't tell me what to do, or think she knew best, but she knew how to help because she's been there" [Supporting Families with Young Children].

> It pretty much is everything we do - all clients or service users be they carers or the person with a disability are those with the expertise into their own situation. I then provide them with information based on this that they may not be aware of or they have requested. Quite often there are opportunities for peer support where lived experience becomes an [sic] resource in mutual self help. Likewise the helping role often is two way in that I may learn things that I may find useful or interesting personally or that I can build up my knowledge base of information which is what makes a support worker more useful after say 4 + years in a particular field [Health and Wellbeing].

Listening to people and empowerment was important for some respondents, and was related to not wasting time and a need for person-centred support:

> Listening to people and helping them feel listened to helps empower people to change their circumstances, and it gives more validity and authenticity to the work that we're doing. It also means that we're not wasting valuable time and resources chasing down dead-end solutions that don't work in practice [Health and Wellbeing].

> lived experience forms the basis for expectations and indicates the needs of the individual for improvement in their experience. this also forms a basis for services to do better, be better and deliver true person centred support as required and when required [Disabilities].

The need for stronger communities was raised by a statutory service, which explained that learning about lived experience could lead to better support:

> Our Fire and Rescue plans says that "the Public strongly supported a focus on preventing incidents and asked the Fire and Rescue Service to work with partner agencies to deliver both a joined-up and targeted approach to ensure support reaches the most vulnerable across York and North Yorkshire. One of the priorities within it is to build stronger communities which can prepare and recover from emergencies. Learning about the lived experiences of some of those most vulnerable people and engaging with different communities could help us to better support more people in achieving these aims [Statutory Service].

4.1.3 How good do you think your organisation currently is at engaging lived experience?

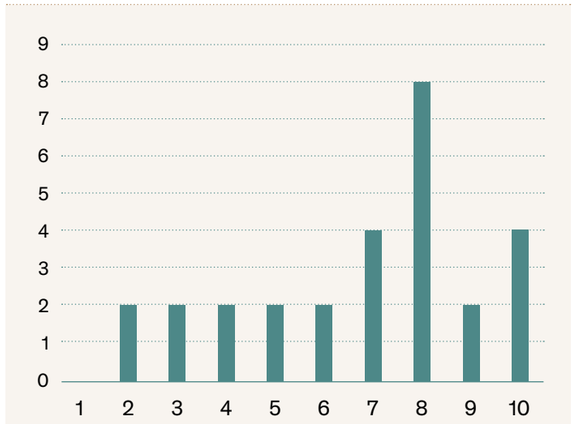


Figure 3: How good do you think your organisation currently is at engaging lived experience? (10 is 'extremely good')

Figure 3 indicates that while most organisations report that they are engaging lived experience relatively well, some respondents rated their VCSE as lower down the scale.

The degree of lived experience involvement varies – some organisations explained that everyone involved in their project have lived experience:

> Our entire staff team and pool of volunteers either have, suspect they have or are main carer's [sic] for someone with a long term health condition or disability [Disabilities].

Some organisations explained how it is important to engage lived experience from the beginning of the project:

> We engage with people and we understand the value and importance of doing this work, however sometimes we could do it better. We could involve people at an earlier stage of the project, or ensure we keep them better updated with projects [Health and Wellbeing].

> Because we listen, we often start from a fairly blank slate and we genuinely want to deliver what people need, rather than trying to shoehorn people into what we want to/are already delivering [Health and Wellbeing].

For others this is not part of their recruitment strategy:

> Whilst everything we stand for comes from a place of lived experience from our founders, we haven't effectively made it a key part of our recruitment so not all of our team have relevant lived experience. We do however aim to make up for this by bringing in people who do and promoting talking and sharing within groups we support [Education and Skills].

One organisation explains that they do not have ongoing dialogue with lived experience for designing and delivering their programmes:

> We actively seek out, receive and respond to feedback, and are good at highlighting how our programmes have supported people in the press, blogs etc. They're very happy to participate which shows they feel somewhat reflected by what we do. But we don't have ongoing dialogue where potential service users support us to design and deliver our programmes, evaluations etc. [Community Support].

> Whether the degree of lived experience involvement is associated with how 'good' a VCSE is at lived experience work is an unanswered question.

One respondent highlighted the importance of the danger of re-traumatisation in lived experience engagement:

> As it is at the core of our service I believe we do well that said their [sic] is always room for improvement. We regularly update our practices in line with our trauma informed ethos to ensure we limit the risk [of] retraumatisation as well as improving how we utilise shared information and feedback progress so lived experience voice is in no means a tick box exercise or a token gesture [Domestic Abuse After-Crisis Support].

Some organisations identified challenges they face in engaging lived experience, including lack of time, resources and capacity, which they perceive as acting to limit their lived experience work:

> Increasing efforts to do this, attempts to establish structures and mechanisms to do so. However, it is challenging in time, resources etc and we probably don't reach either the numbers or range of people we would like to [Community Support].

> Lack of staff time to do the research, engagement and planning that is needed [Disabilities].

> 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. 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].

> We probably do a good job for the majority of our community but one size doesn't fit all. It's hard when resources are limited to reach out and engage and meet the needs of everyone [Health and Wellbeing].

> I don't see enough attempts being made to do this. From the hospital trust point of view, services are not shaped according to user experience or need, they are more shaped due to organisational pressures [Community Healthcare Team].

The idea that engaging lived experience takes time was explored further by some respondents:

> 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 organisation [Community Support].

As is the need for training:

> It's a difficult question to answer, and I can only give a subjective answer because there will be pockets of work that are going on that I am unaware of I'm sure e.g. in recruitment. From my perspective, within the Prevention Team I think we are quite good - I've arranged for Lived Experience equality and diversity training for the team and we spend a lot of time engaging with different community groups and furthering our own knowledge about the areas where we work [Statutory Service].

4.1.4 What you do right now that works?

The survey asked respondents what they do right now related to lived experience that works. Examples of perceived good practice included:

> Open doors, someone on hand at all times [Community Support].

> Outreach work to tell people what we provide and ask what people need - finding out about gaps in support in the community - carer support service. Collaboration with existing services which are already well used e.g. Macmillan coffee morning [Health and Wellbeing].

> Spend time out in the community, attend engagement events and mix with people, staff networks [Statutory Services].

One respondent highlighted creativity:

> We really push for people to think outside the box when it comes to engaging with people and look for ways to do it in a creative way, that means people get something out of the opportunity too [Health and Wellbeing].

Filling gaps, predicting problems and future-proofing were also identified:

> helping others and filling gaps that exist, and also predicting problems and solutions to futureproof the organisation and help the community [Advocacy].

One organisation explained how over time, they have learned what works for their members:

> Our activities have developed through experience of what works and doesn't work for our members. Example 1 - we used to provide food for parties but have realised our members enjoy bringing food to share. To give and contribute boosts their self esteem and identity. Similarly, some members want to help with setting up and setting down and washing up. We used to worry about insurance and urged them to leave these tasks to staff and volunteers but we now support them to help instead of trying to stop them [Health and Wellbeing].

One organisation explained their use of a 'bottom-up' approach which is informative for their members:

> Use bottom-up approach - what is important to them and inform them of the impact of them sharing their lived experience so it is purposeful [Health and Wellbeing].

For one respondent, success was connected to engagement taking place at a high level within their organisation:

> Engaging people at the beginning and ensuring it's high level involvement - working together and deciding together [Health and Wellbeing].

One respondent discussed the need for working in partnership alongside existing specialist groups and the need for having a consistent engagement brand which can reach more people:

> Trying to work better through and with key VCSE organisations - Community Anchors - and specialist groups recognising their potential to reach further than us sometimes. Continuing to use existing groups - work being done by adult social care on eg reaching older people, people with learning disabilities. Also developing wider consistent engagement brand to reach more people "Let's Talk ..." . Generic but keep working to extend inclusivity [Community Support].

Another respondent explained how they enjoy working alongside volunteers, and more crucially, that for them, the success of a project is not just about saving money:

> I think it is 20 years + in helping role and longer when it comes to transferable skills work....lots of diverse experiences and insight - my team are respectful and supportive and I really enjoy working with and alongside volunteers so it is not just about the money which is ..... [Health and Wellbeing].

The role of partnerships was highlighted:

> partnerships, reach of people accessing our services [Community Support].

> [our lived experience engagement is] pretty good actually … within our local service it is excellent - we are a great team who are passionate about what we do and helping others through difficult times. Gaining feedback from our service users is something we do all the time in order to know that we are on the right track...There is however maybe more scope for service development but I am currently doing this by encouraging service users to get involved in planning things - I did develop a children's peer support group years ago and most people like to be in the driving seat when it comes to making choices about what affects them even if it is a simple one. Respect and treating others as you would like to be treated also comes into it and some knowledge of theory and practice of social work is advantageous in understanding - partnership working... [Health and Wellbeing].

One respondent noted the need to:

> involve parents & kids in deciding what the charity should be doing to help them [Disabilities].

The need to share opportunities and get feedback was discussed:

> Client to volunteer pathway. Sharing opportunity for lived experience voice to be used for positive change. Focus groups for improved delivery practice. Creating multiple positive social networks. Including the whole family with the use of family activities. Multiple options for inclusion, surveys, online and in-person. Open-door policy for ideas and feedback [Domestic Abuse After-Crisis Support].

> We actively seek out, receive and respond to feedback, and are good at highlighting how our programmes have supported people in the press, blogs etc. They're very happy to participate which shows they feel somewhat reflected by what we do [Health and Wellbeing].

> We have done some events to engage people in our ageing well agenda, which has been well received. I think we work well across service boundaries and with local partners across the Selby area [Community Healthcare Team].

Advocacy was discussed:

> Engage with group members to see what they would like/ require. Increase visability to help them feel accepted and included. Advocate on their behalf. LGBTQ+ remain uncatered for particularly the transgender community [Health and Wellbeing].

Active listening was identified by three respondents as a technique which they find useful for engaging lived experience:

> We actively listen to our clients, allow them to share their lived experience without preconception or judgement, and synthesise their lived experience to help them through the challenges that they face. This is reflected in the feedback that we get from clients that have been on our programmes [Community Support].

> We actively listen to our clients, allow them to share their lived experience without preconception or judgement, and synthesise their lived experience to help them through the challenges that they face. This is reflected in the feedback that we get from clients that have been on our programmes [Community Support].

> Actively listen give people our time. Give appropriate support we are non-judgemental, we care [Health and Wellbeing].

One respondent explained the need to take time in the process, really considering the purpose of engagement and who benefits from it:

> We have learnt to take our time and consider why we are asking for engagement and who is it benefitting [Domestic Abuse After-Crisis Support].

Finally, one respondent explained the profound effect on them of lived experience engagement, and its role in keeping services patient centred:

> Whenever I have attended any lived experience events, it really has a profound effect on me as a practitioner. I think more practitioners/ clinicians / health care managers should attend such events regularly, as it might help keep services patient centred [Community Healthcare Team].

4.1.5 What have you tried that didn't work?

One organisation explained that they are currently reviewing their organisational structure, and questioned the extent to which people are supported to give feedback, and the influence that feedback has on their organisation:

> There are opportunities for people to give feedback but I am unsure the extent to which people are supported to do this and how much influence opinions have over how services change. There is a current review ongoing regarding structure of my organisation and I know they are considering feedback from the people we support when making decisions about changes [Community Support].

A respondent explained the danger of decision makers thinking they know best, which leads to funds being wasted on gimmicks with unsubstantiated buzzwords:

> People with decision making power tend to think they know best and don't work collaboratively with clients to engage in the process. Funds spent on gimmicky things. Buzzwords being used but unsubstantiated [Health and Wellbeing].

One respondent observed that their lived experience engagement may be due to more luck than good management:

> We work with hard to reach communities/individuals - are we targeting lived experience - probably not, it may be more of more good luck than good management [Environment].

Asking the wrong people was highlighted by one respondent:

> Asking the wrong people about barriers - if you haven't lived it you can't possibly know the reality! [Disabilities].

For another, the danger of people claiming to be 'the voice of' a particular group (e.g. the voice of everyone with mental health challenges) was discussed by one respondent:

> Can't think of a specific example but concern that some special interest groups can act as "gatekeepers" and claim to be "the voice of ..." when we would like to hear as many individual voices as possible [Community Support].

A lack of understanding about coproduction was raised by one respondent:

> We held a series of public events to ask people for their thoughts on how well we were doing with engagement and coproduction but the events didn't seem to work due to not many people understanding what we meant by coproduction [Health and Wellbeing].

Not having enough time to establish trusting relationships was observed by one respondent:

> Our work with young people and engagement hasn't been as successful as it takes time to build trust and credibility [Health and Wellbeing].

Barriers to funding and legal complexity was raised by one respondent:

> Progress is slow. Application for funding was rejected by the town council for this year 2025. Too many barriers put in place re-funding support like having to be a legal entity when there is no one within the group that I know of with experience or the confidence to expose themselves to possible rejection and fears around safety [Health and Wellbeing].

Four respondents reflected on a lack of longer-term funding, and therefore time and capacity, as being a key problem:

> We don't do a particularly good job at this: partly because funding is so short term, so we don't have capacity to build in lots of time to have these conversations in the right way or the capacity to step back and really think about how we could do this well [Community Support].

> … we just have stumbled at how tricky it would be. We have governmental guidelines and very complex/nuanced barriers (language, stigma) and we just haven't felt we've had the capacity, time (our funding is time limited and comes and goes very fast) or skill [Health and Wellbeing].

> This needs time in the workplace to get this there needs to be more, this comes down to money unfortunately [Health and Wellbeing].

> Perceived barriers are resources and time needed [Health and Wellbeing].

One respondent identified a complicated problem, whereby people seek to volunteer, driven by a desire to 'give back' to the organisation, when they are not yet ready for the role:

> Many families, at the end of their support with us, are keen to volunteer and 'give back' but sometimes a parent is not ready for this and struggle to differentiate from the supported to the supporter; often a bigger time gap is required to separate the two roles. It is important that the person with lived experience is in a position to separate their own needs from that of the person requesting help; they need to be ready to recognise that shift in focus [Supporting Families with Young Children].

Similarly, one respondent described the potential of danger to clients' health and wellbeing from participating:

> We have put further detail into our client to volunteer pathway as individuals can be set on getting into this line of work and then realise it's not good for their health and wellbeing. We will be relaunching our Co-production Board which we put on hold as we realised more direction was required. [Domestic Abuse After-Crisis Support].

One respondent discussed acknowledging their own identities as white, middle class non-disabled people trying to do good as a barrier to success:

> Those we're hoping to reach often struggle to engage with traditional support systems. Things like positioning and perception, imagery, tone/vocabulary are very important to get right in order to appeal to the audience. Essentially, we're a bunch of white middle class non-disabled people trying to do good - but how do we make sure this actually connects with those we're trying to support? [Community Support].

The potential of the organisation having an agenda which differs from what the service users want was identified:

> Going with an agenda when they want to talk about what matters most to them, which isn't always what you set out to find [Health and Wellbeing].

Similarly, the fact that clients may not wish to be engaged was raised by one respondent:

> Engaging with people that are identified by funders - but do not want to be engaged [Environment].

Engaging lived experience in VCSE activity – phase 1 detailed account

Having a large catchment area with transport and technology restrictions was viewed as a key challenge by one respondent (this is a particular problem in rural North Yorkshire):

> Because my catchment area is vast - I had wanted to develop a lived experience voice group but that did not happen due to transport and technology restrictions [Health and Wellbeing].

A need for training in compassion and engagement was raised by one respondent, but it is unclear who they think needs training (professionals or service users):

> We assume everyone who works for us and we assume they understand. Training is needed compassion and engagement sometimes needs to be learned [Health and Wellbeing].

A lack of co-ordination between agencies and a lack of promotion of activities was discussed as a cause of low take-up of opportunities:

> We tried a wellbeing drop-in in Selby - but without coordinating with others, and not enough promotion. Very little take-up [Health and Wellbeing].

Similarly, one respondent raised poor and impersonal promotion as a barrier:

> Standard, impersonal marketing and advertising like flyers and SM posts [Education and Skills].

Competing concerns and scepticism were discussed:

> Bit tricky sometimes as part of a Local Authority as there is often a need to balance a lot of different concerns / parts of the organisation if trying to do large scale engagement. Can be easier and quicker to try to work with / through e.g., a VCSE partner but can lose some "control". People can be quite sceptical of our authenticity in seeking to engage [Community Support].

One respondent described a specific incidence of difficulties when introducing creative approaches:

> We tried introducing more creative dance and improvisation into our dancing but only a few of our members welcomed this [Health and Wellbeing].

Finally, one respondent explained that they need to better understand the difference between engagement and consultation, and explained the frustration which can emerge from their views not being acted on:

> It would useful to understand better the differences between engagement and consultation. Some of the members of our groups are carers of and people with dementia. I know what it's like to be asked for my views and know they're not likely to be acted on either because of lack of resources or because it's really hard to cater for so many different individual situations and needs. There are times when I feel the experience I'm living through and my needs are really understood and taken into account by people and organisations who help me. The daycare service I use for my husband is set up and structured in a way that really helps me. And many of their staff really get what life is like for me/us and that helps enormously. I happily contribute to this organisation's consultation exercises because I know they will act on my views if they can. E.g. they started providing daycare on bank holidays and emailing carers a daily report of activities and meals in response to views we expressed [Health and Wellbeing].

4.1.6 Do you want support with your lived experience engagement?

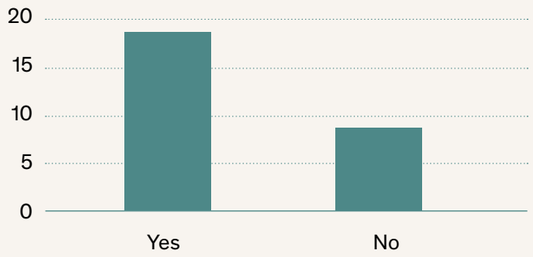


Figure 4: Do you want support with your lived experience engagement?

The questionnaire asked what support or services they would find useful to engage lived experience (figure 5). Of the 17 who answered the question, four respondents selected all of the options. This suggests a real appetite for change and development of lived experience engagement among the responding VCSEs.

Tool kits and other resources seem to be popular, selected by 14 of the 17 who responded: we identified several toolkits already available to VCSEs, for example, the Institute for Healthcare Improvement; Mind; South East London Integrated Care System; and 100 Million Healthier Lives.

Figure 4 shows whether VCSEs want support with their lived experience engagement. It is interesting that roughly one third of respondents indicated that they do not want support. This may be related to those respondents who indicated that they think they are already doing lived experience engagement well (figure 3, page 38).

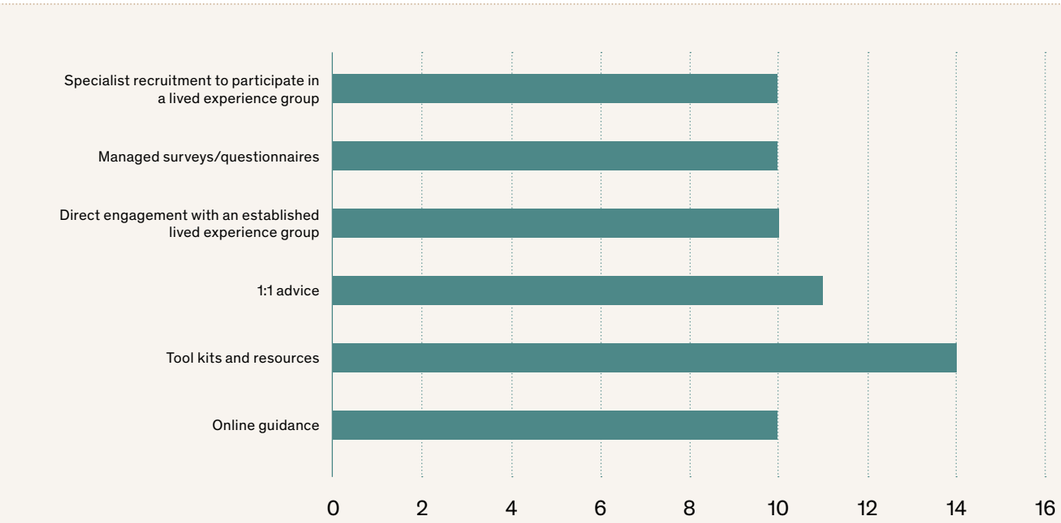


Figure 5: What support or services would you find useful to improve your organisation's lived experience engagement?

4.2 NAVCA questionnaire

The National Association for Voluntary and Community Action (NAVCA), the national membership body for local infrastructure organisations which support the voluntary and community sector was of interest to CERT as a potential means to extending the potential reach and impact of our project beyond UfY and the Selby locality. NAVCA supports over 165,000 charities/community groups across the UK. We wanted to explore their infrastructure perspective on lived experience engagement. The questionnaire covered areas of interest to us, including:

- What does 'lived experience engagement' means to you?
- How important is lived experience engagement to your infrastructure work?
- How important do you think lived experience engagement is to the organisations you work with?
- How good do you think your organisation is at directly engaging lived experience?
- How good do you think your organisation is at supporting other organisations to engage lived experience?
- What you do right now in engagement that works? For example, what methods have you used (e.g., specialist recruitment, self-referral, group sessions, questionnaires)?
- Who have you worked with and what successful projects have you run?
- What have you tried that didn't work? Why do you think it didn't it work?
- What would your ideal future for lived experience engagement look like?
- What support do you need for you as an infrastructure organisation?What support do you need for you to work with the organisations you work with?

Eight respondents completed the questionnaire (it was sent to just under 200 organisations).

4.2.1 What does 'lived experience engagement' mean to you?

Respondents explained that for them, lived experience engagement means hearing and involving community groups and individuals with direct experience of the situation/ service of importance:

> Lived experience to us is someone who has direct experience of a social issue and/or of accessing services. For example, someone may have lived experience of poor mental health or poverty.
>
> Ensuring people and community groups with different identities and experiences are heard and involved.
>
> Engaging with people with real life experience directly linked to the topic - so eg if you are talking about accessible council buildings, making sure you talk to the disabled community including blind and deaf and their carers (if they have one). If you are looking at a housing strategy think about the homeless too - things like that.
>
> speaking to people who have lived through past and/or present a challenge you're designing a service or product to help.
>
> Consulting and speaking to people who have experience through their general lives around specific issues or areas that you are consulting on.

One respondent explains the importance of all of their Board having lived experience of disability:

> We're a unique lived experience organisation that also delivers infrastructure support, so its integral to everything we do. 70% of staff (approx) and all the board have lived experience of disability and we use our lived experience in our day to day work.

Finally, one respondent cautioned the danger of an 'us and them' approach which may arise from this way of working:

> Lived experience engagement implies an 'us and them' approach - we have to engage them. Ideally we would talk about involvement rather than engagement.

4.2.2 How important is lived experience engagement to your infrastructure work?

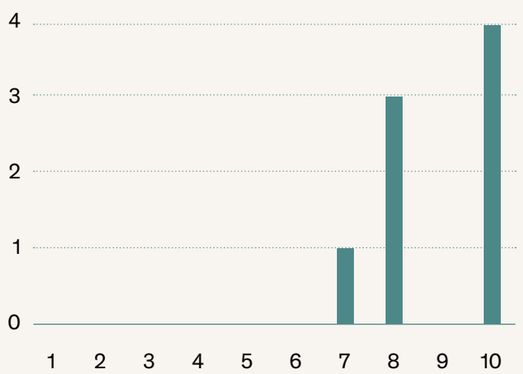


Figure 1: How important is lived experience engagement to your infrastructure work? (10 is highly important)

Figure 1 indicates that the responding organisations generally view lived experience engagement as extremely important. For one respondent:

> It's our whole organisational approach.

Several respondents justified their answer by arguing the need for individual voice and for individuals with lived experience to speak for themselves, rather than relying on other people (e.g. organisations) to speak for them:

> It's always better for people with lived experience to speak for themselves, rather than speaking for them.

> Individuals voice is important when developing new services to ensure services are codesigned and delivered in effective ways that suits the needs of relevant cohorts of people.

One respondent explained that their organisation has invested considerably in developing their lived experience work, which they coproduced with their stakeholders. They also devoted effort to employ a lived experience consultant to champion this work and directly influence their lived experience engagement:

> Lived experience is very important to our work and over the past few years we have invested a lot in developing our lived experience work further. For example, we launched a local voices framework which was coproduced with our members, partners and people with lived experience. We have also invested in a lived experience consultant who is supporting our members with developing their lived experience work as well as championing for the principles in our local voices and for people with LE to be involved in decision making.

Other respondents emphasised the importance of engaging with VCSEs in order to meet the needs of their beneficiaries and communities:

> We exist to provide services that meet the needs of our beneficiaries and their communities - we cannot do that without engaging with the VCSE and understanding what is important to them. With a partner we do community engagement and again it is important to target that appropriately

One respondent identified that without knowing what the issues are (achieved through lived experience engagement), the service cannot be designed as you will not know what the important issues are:

> Up until recently the team might have said not important, but for the past 18 months we've been doing user research and the results have spoken for themselves, we cannot design a service to help people unless we know really know what their actual issues are

4.2.3 How important do you think lived experience engagement is to the organisations you work with?

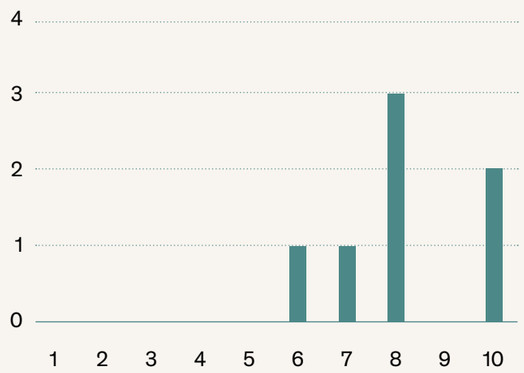


Figure 2: How important do you think lived experience engagement is to the organisations you work with? (10 is extremely important)

Figure 2 shows that respondents think that lived experience engagement is of relatively high importance to the VCSE organisations that they work with.

One NAVCA respondent indicated that without lived experience engagement, their infrastructure organisation may well not exist. Two emphasised the importance of needing to tailor services to individual needs/delivered in an effective way for their clients:

> Because without they might as well not exist - need to tailor/adapt/provide the correct services in the right way.

> Lived experience engagement is important to organisations that we work with to ensure services are delivered in an effective way for their client groups.

One respondent explained that lived experience is very important to their organisations, and observed that smaller organisations are often fully led by individuals with lived experience. However, they caution that funding and capacity can be a problem where lived experience engagement is not properly resourced and funded.

> I think lived experience is very important to the organisations we work with and a lot of smaller organisations are fully led by lived experience. Even though there is a real commitment from members, it is difficult due to funding challenges and their capacity as well lived experience isn't often resourced properly.

One respondent observed that some organisations do not have the skills and resources to implement their equity and inclusion principles:

> There is good awareness of equity and inclusion principles within our local sector, though organisations don't always have the skills and resources to implement this.

Another respondent indicated that for different organisations, while the importance of lived experience to the VCSEs they work with varies, its importance is increasingly recognised:

> It's [lived experience engagement] variable, but there's a definite recognition that it's important and when I did a workshop on lived experience leadership last year 50 people signed up.

4.2.4 How good do you think your organisation is at directly engaging lived experience?

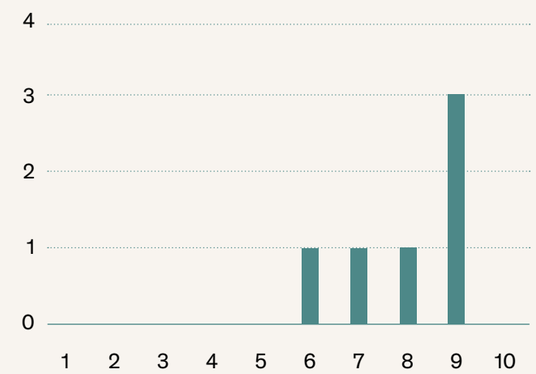


Figure 3: How good do you think your organisation is at directly engaging lived experience? (10 is extremely good)

Figure 3 shows that the respondents think they are generally good at directly engaging lived experience in their work.

Some respondents explain that engaging lived experience is fundamental to how they work:

> It's how we work, although of course there are always more experiences we could include.

One respondent proceeded to explain how they achieve lived experience engagement:

> I think we are good as we proactively engage with people with lived experience through different areas of our work such as Food Partnership and the Beans on Toast Group, financial resilience forum and working together with people who have experience of food insecurity and financial hardship to influence our work. We are also in the process of developing a lived experience leadership programme to support people with lived experience to build confidence and provide skills and development support to help strengthen lived experience and support people into volunteering and paid work opportunities with our members. Our lived experience consultant who is leading on the work has lived experience herself and been involved in various projects sharing her experiences so we feel we are trying where possible to directly engage with lived experience.

One respondent expressed concern about a lack of skills and resources in their organisation and anxiety about wanting to avoid 'taking over' lived experience groups.

> Lack of skills and resources to do more, lived experience groups representing themselves and us not wanting to get in the way or 'take over'

Another respondent commented that they found this question harder, explaining that their organisation is either really good or struggling, especially where they haven't thought the problem through properly or where there are challenges related to the project timeline as dictated by funders:

> This is tricky to score - depending on what the work is we can either be really good at it or struggle terribly so I've left it in the middle. Struggles sometimes occur if we haven't thought it through properly and/or if the capacity of those we want to engage isn't there (ie we probably got the timing wrong). However sometimes the engagement timeline is dictated by a funder and is out of our control

One respondent identified room for improvement as lived experience engagement is not something they do by default as an organisation:

> Room for improvement, at the moment it only exists in a small pocket. It is not the default thinking when we have a problem.

4.2.5 How good do you think your organisation is at supporting other organisations to engage lived experience?

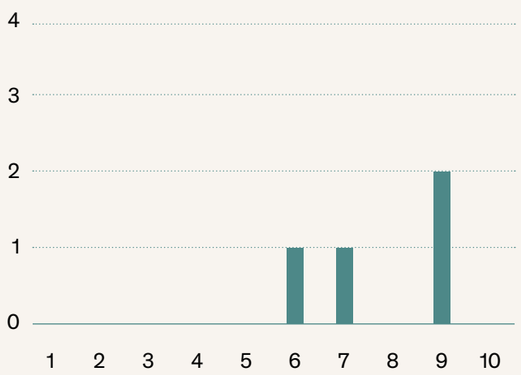


Figure 4: How good do you think your organisation is at supporting other organisations to engage lived experience? (10 is extremely good)

Figure 4 indicates that while some respondents think their organisation is relatively good at supporting other organisations to engage lived experience, some were less confident about this.

One respondent explained that lived experience engagement is viewed as a priority for their organisation:

> We model it and communicate it as an organisational priority

Another respondent explained the lengths they have gone to directly engage lived experience:

> Through our lived experience consultancy offer, we provide bespoke support for organisations to help develop their lived experience including 121s, training and workshops. We have also set up a local voices network to bring together people with lived experience and organisations to learn best practice, share learning and support each other when it comes to lived experience and coproduction work.

One respondent discussed getting the language right, and the need to ensure that lived experience engagement is meaningful not tokenistic:

> I've just started working on this, but I'm finding it difficult to get the right language and make sure it's not engagement for engagement's sake, we actually have to make it meaningful

For one respondent, while they practice lived experience engagement in specific projects, they see a need for wider research to support voluntary groups more generally:

> We engage in this type of work through specific projects - where voice and influence is a specific outcome - however I believe there is a wider piece of work that can be undertaken to support voluntary sector groups in general.

One respondent explained that while they engage lived experience effectively with local partners, but they do not need to provide much support to their VCSEs as they believe the lived experience groups do it for themselves already:

> We do this effectively with local partners (e.g. local authority) in our representation work, but don't provide much support to the sector in this area, mostly because lived experience groups undertake their own training / influencing work and build their own cross-sector relationships, and also because of our time, skill and resource

4.2.6 What you do right now in engagement that works?

Various approaches to lived experience engagement in VCSE activity were described. One respondent explained that they use a huge range of approaches: workshops; questionnaires; group sessions; one-to-one meetings; a local voices network; and a lived experience consultant. They also identified their projects which were fully designed and led by those with lived experience:

> We run a number of workshops, questionnaires, group sessions and 121s. Also through our local voices network too and with our different alliances, we provide engagement opportunities. We also fund a lived experience consultant to lead on this work too. Successful projects include meeting places work, [redacted for anonymity]…and Poverty Awareness Training which was fully designed, led and delivered by people with lived experience. Other projects include Positive Mental Health For Us and other various projects too.

Another respondent also described using lived experience groups and one-to-one relationships:

> We run a formal VCS representation programme which has reps from lived experience groups; we build 1-2-1 relationships with by/for groups and support them in their work

One respondent described using group sessions, case studies, referral processes and questionnaires to engage lived experience:

> Group sessions with children and young people
> Monitoring and case studies
> self-referral and organisation referral mechanisms for First Steps Forward
> Questionnaires

Another respondent explained that their organisation runs a specialist consultancy to embed coproduction, with most roles specifically kept for disabled people. They also talk about disabled people writing to them directly to share their experiences:

> We run a specialist consultancy that worked to embed coproduction in our local ICS; we reserve most roles for disabled people and advised ACAS on developing guidance around the legal ability to do this; we have a long running project with the royal free gathering intelligence from local groups to make healthcare more accessible; we have disabled people writing to us about their experience of the benefits system through our campaigning and we systematically gather intelligence from our front line work.

One respondent described the origin of their lived experience engagement approach, explaining that they have used prototype workshops to gather feedback on three tools they have created to support lived experience engagement:

> The kick start for all this was going on the CAST led Deloitte Digital Connect Programme in 2024. I was supported for six months (alongside 30 other charities) to take a problem we had and use the three phase design thinking methodology (discover, design, deliver) I used user mapping, unstructured interviews, prototype workshop with what if questions and surveys, group discussion etc - we've been prototyping and gathering feedback for the past 6 months on 3 tools we're now sharing out to the sector that work to widen access to volunteering.

4.2.7 What have you tried that didn't work?

One respondent observed that online meetings can be problematic:

> I think user groups are pretty sick of zoom meetings!

Another respondent noted market saturation:

> Surveys and questionnaires - this is a saturated market and people can just get turned off by them

On the other hand, one respondent explained low attendance was the consequence of meetings being face-to-face where people did not want to travel. They also considered that low attendance could have been caused by unintentionally using off-putting language:

> the prototyping workshop didn't get as much attendance as I would have liked, I know this was in part because it was face to face and people didn't want to travel (we covered costs), I wonder also if the language put them off I probably used the word prototype!!

Two respondents highlighted less success with open invitations (where few people attend events), and suggested that this is because time is needed to build relationships, safe spaces and trust:

> We did try for one project, setting up face to face workshops and inviting people there to which we only had a couple of people turn up. We think it didn't work because we've found we need to go into trusted spaces in the community and build relationships up with people.

> We have had less success with open invitations to events. Time is needed to build trust and to ensure safe spaces before lived experience groups will attend. More successful after lots of 1-2-1 relationship building.

4.2.8 What would your ideal future for lived experience engagement look like?

One respondent explained that lived experience engagement is:

> …integral to our organisation and always will be.

Another respondent highlighted the need for people to have the opportunity to share their experiences:

> All people have the opportunity to share their experiences so people are more involved in services.

One respondent gave a practical answer, that they would use lived experience in deciding how to make their volunteering more inclusive:

> Every volunteer involving charity would speak to people in their community as a first step when they are thinking about how to make volunteering more inclusive.

For another respondent, lived experience engagement would be the norm, embedded within organisations – where people with lived experience are equal partners and able to lead on work:

> An ideal future would be it becomes the norm that people with lived experience are considered equal partners and involved in coproducing services, policies and decisions that impact their lives. That our member organisations are able to embed lived experience within their organisations and that actually people with lived experience lead on the work too where possible.

One respondent observed a need for more people with lived experience in their staff teams, arguing that this would remove the need for specific lived experience engagement work:

> More people with lived experience are part of our staff teams and are delivering work, which enables us to build trust and to welcome more people with lived experience into our spaces day-to-day. This removes the need for specific lived experience engagement work.

Finally, one respondent seeks to drop the title 'lived experience', replacing it with 'engagement':

> I like to see the title 'lived experience' be dropped and it just be engagement and that the automatic response is to be open and able to engage everyone.

4.2.9 What support would you like for you as an infrastructure organisation:

The need for adequate funding to support lived experience engagement was highlighted as a key concern by several respondents:

> more funding is always welcome, particularly around comms and campaigning. Campaigning resource (including hearing people's voice) is hard to access.

> Tools, guidance and funding.

Other respondents added stakeholder support, and the opportunity to learn about best practice/peer learning/evidence base from other similar infrastructure organisations.

> Funding support is a massive one, as an infrastructure organisation as we don't do direct delivery, we are limited to the funding we can apply for which can make it difficult to resource our lived experience work. Stakeholder support too, it would be great to learn from other infrastructure organisations who are doing this work to share learning and best practice with each other.

> Peer learning

> Support to share evidence on what we're learning, as a Volunteer Centre I feel we hold a key role in doing the data crunching, understanding what the needs of our community are and testing tools to see what works. We need support to share out that evidence base to the sector and provide them the space to digest the evidence and try the tools out for themselves. Building user engagement in as a first step in any kind of problem solving could be built into tools like the Investors in Volunteering award.

One respondent observed the need for relationship building and trust so that people want to get involved in their activities, including becoming trustees:

> Opportunities that upskill our staff to build relationships of trust, so that diverse people want to be involved in our work including attending events, applying for our jobs and trustee roles.

4.2.10 What help do you need to work with the organisations you support?

Again, respondents raised funding and capacity as a key requirement:

> Just more infrastructure funding.

> Again funding and capacity… we find that a lot of our organisations have limited capacity to even run their services at the moment therefore, lived experience work can be tricky as you do need time and resources to make sure it's done properly.

> Funding to ensure additional capacity is made available to ensure that this can be done in an effective and meaningful way across all services.

Other respondents suggested a need for tools, guidance, case studies and other resources to support lived experience engagement:

> Tools and guidance too, our lived experience consultant has been creating tools and resources to support our members as well as the bespoke work but it would be great to again have a space where members can see what's happening in different areas too.

> Case studies from other orgs

One respondent suggested the need to develop an evidence base of what works in infrastructure organisations to move away from being stuck in old ways of working. They also argue for a need for more skills, knowledge and training to support this:

> I see people who recruit volunteers stuck in old ways of working. We need a really strong evidence base to say why we need change and I think doing this by demonstrating how it works in infrastructure orgs who can lead the way on this. More skills, knowledge, training and support for infrastructure orgs to lead on user led engagement and share findings more broadly.

5. Strategy for phase two

Phase one provided us with both an academic understanding of lived experience in VCSE activity and the perspective of UfY stakeholders on these findings. A key achievement has been the establishment of good working relationships with UfY and stakeholders, where there is significant engagement and interest in the project. This is largely related to the considerable good will UfY has with their community partners who came forward to participate in this project when invited by UfY to become stakeholders.

Phase two has been *co-designed* and *co-funded by UfY*. The CRG follow-on funding awarded to this project will allow CERT to work with UfY and the stakeholder group to apply phase 1's learning to developing UfY's future operating model. This phase will collect *evidence of impact* of the interventions and will involve further *dissemination* in terms of resources to support lived experience engagement. This project also sets YSJ/ISJ up for future collaboration with research partners in Selby and nationally via NAVCA.

Phase two activity:

There are five strands to phase two of the project:

1. ***Lived experience group:*** This group will be established by UfY with support from CERT. The opportunity to join this group will be openly advertised locally by UfY – the participants will be drawn from the Selby community as broadly as possible. There will be a maximum of 15 places. Monthly meetings, until May 2026 (eight sessions) will be facilitated by UfY (Chris Hailey-Norris). The group will apply learning from phase 1 into real world VCSE activity. Directly addressing lived experience in UfY's VCSEs, the lived experience group will act as consultants to UfY's VCSE partners, advising these partners about their lived experience practice
2. ***Evaluation and research group (ERG):*** this group will include CERT researchers, UfY staff and other stakeholders – advertised to the Selby community at the same time as the lived experience group. This group will have a maximum of 10 participants. The role of the ERG will be to broadly evaluate the impact of the Lived Experience Group. The ERG will meet monthly until May 2026.
3. ***Bespoke CERT research methods course:*** CERT will deliver a research methods course to the ERG. This course will focus on the methods most relevant to their needs in this project. This is to ensure that ERG participants are equipped with skills they need to be fully engaged in the evaluation of the lived experience group.
4. ***Evaluation of the lived experience group:*** The success of the lived experience group will be evaluated by the ERG supported by CERT. The evaluation methods and approach will be decided on by the ERG following their research methods training.
5. ***Reporting and development of resources for dissemination*:**

Following the completion of the evaluation, the findings will be broadly disseminated, including:

- Dissemination of findings via a sharing event for stakeholders and the public in Selby.
- A written report, including a plain language summary, will be created collaboratively by ERG and CERT.
- Resources to support lived experience groups in VCSEs will be developed by ERG and Lived Experience Group. Resources will be shared broadly, including with NAVCA, leading to national impact.

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