

Lived experience engagement in voluntary, community and social enterprises

A summary of research literature by the Converge Evaluation and Research Team

December 2025

UP FOR YORKSHIRE

CERT
Converge Evaluation and Research Team
insight through experience

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Literature review scope

The purpose of this literature review is to explore what is currently known about lived experience engagement in voluntary, community and social enterprises (VCSEs).

This review 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 York St John University's Institute for Social Justice. The project asks the questions:

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

How can we support those with lived experience to participate purposefully?

This review includes:

- Reasons why VCSEs might choose to collaborate
- The benefits of coproduction (for service users, charities and society)
- The barriers to coproduction
- Ways of collaborating, such as:
  - Strategic buy-in
  - Organisational culture
  - Skills and resources
  - Communication
  - Relationship building
  - Ethics
  - Ensuring accessibility

Project partners

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, specialising in participatory evaluations of community mental health related projects across the country.

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

Why collaborate?

- 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 is 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).
- Lamb, Seifu and Chapman (2023) write: "The charity sector is finally waking up to the value of lived experience… Charities that draw on lived experience can have a stronger identity, better engage their audiences, and deliver more impact. People engaging with or working for charities who have lived experience of the challenges the charity is tackling often report new skills, more confidence, and a greater sense of belonging… Centring lived experience has the potential to greatly increase the impact of our sector" (p4).
- Without a strategic approach, charities:
  - Cannot make the most of lived experience
  - Risk being tokenistic which can lead to more harm than good
  - Fail to move beyond individual involvement activities or one-off approaches
  - Struggle to understand what impact lived experience has had on outcomes (Lamb, Seifu and Chapman 2023, p4).
- "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).
- The features of co-production typically include:
  - Recognising people as assets;
  - Including all perspectives and skills;
  - Supporting people to meaningfully share and participate;
  - Public services becoming change agents that facilitate people's inclusion;
  - Everyone benefiting from working together;
  - Developing networks of mutual support.
  - Fundamental to co-production is the meaningful inclusion of people who are not already 'in' the organisation developing or delivering the service. It means recognising the experiences and skills of recipients of services, or local communities: something that is not always easy for service providers with targets and established ways of working (Coutts, 2019).
- Building Social Capital, trust and relationships (Hatzidimitriadou et al., 2012) including more effective cooperation between people from organisations and across disciplines (Man et al., 2019).
- Shared norms (Hatzidimitriadou et al., 2012).
- Drawing on existing local resources and community capacity (Hatzidimitriadou et al., 2012).
- Building skills and developing support (Hatzidimitriadou et al., 2012).
- Increased confidence and engagement (Man et al., 2019).
- New and stronger social connections (Man et al., 2019).
- Improved knowledge of users' needs and responsiveness to them (Man et al., 2019); clearer understanding of the audience's needs (Mind nd).
- Better ideas (Man et al., 2019).

Benefits of coproduction

Benefits for Service Users

- Finding meaning and purpose (Newton, 2022).
- Sense of belonging and feeling understood (Newton, 2022; Hatzidimitriadou et al., 2012).
- Feelings of hope and inspiration (Newton, 2022).
- Being more trusting of services (Hatzidimitriadou et al., 2012; Newton, 2022).
- Better connected with services that meet their needs (Mind nd).
- Improved wellbeing (Newton, 2022; Pollard, Suddert and Tiratelli, 2021).
- Feeling empowered (Hatzidimitriadou et al., 2012), motivated and valued (Mind nd).
- Tackling the stigma of mental illness (Hatzidimitriadou et al., 2012).
- Building capacity of communities to deliver public health services (Hatzidimitriadou et al., 2012).
- Compassion and empathy (Newton, 2022).
- Greater satisfaction and loyalty from service users (Man et al., 2019).
- Feeling connected to their local community (Mind nd).
- Peer support, friendship and solidarity (Newton, 2022; Mind nd).
- Increase confidence and self-esteem (Mind nd); (Newton, 2022).
- Improved skills (Mind nd), knowledge and opportunities (Newton, 2022).
- Services that meet people's needs (Mind nd).

Benefits for Charities

- A reason for existing or surviving; doing what is needed in the community (Newton, 2022).
- Greater involvement with and learning from communities (Hatzidimitriadou et al., 2012; Newton 2024; Parsfield et al. 2015).
- Simple but smart solutions to complex problems (Newton, 2022).
- People want to give back (Newton, 2022).
- Shift of professional attitudes (Hatzidimitriadou et al., 2012); workforce improvements (Newton, 2022).
- Financial gains (Hatzidimitriadou et al., 2012) including cheaper development costs (Man et al., 2019).
- More credibility with funders and the public (Mind nd; Newton 2024; Newton 2022).
- Providing culturally appropriate services (Hatzidimitriadou et al., 2012); greater inclusivity and diversity (Newton 2024); Improved access and inclusion (Newton, 2022).
- Better, more informed decision making (Man et al., 2019; Newton, 2022; Newton, 2024).
- Improved service design and delivery (Newton, 2024).
- Increased accountability and transparency (Newton, 2024).
- More empowerment and advocacy (Newton, 2024).
- Enhanced volunteer and staff motivation (Newton, 2024).
- Wellbeing dividend (Parsfield et al., 2015).
- Long-term sustainability and resilience (Newton, 2024).

Benefits for society

- Contributes to broader social change (Newton, 2022).
- Improve community wellbeing, resilience and cohesion (Pollard et al., 2021).
- Enhance democratic participation and boost trust (Pollard et al., 2021).
- Combats stigma and discrimination (Newton, 2022).
- Challenges people about their privilege, power and position in society (Newton, 2022).
- Citizenship dividend (latent power within local communities) (Parsfield et al. 2015).
- Economic dividend (saving money) (Parsfield et al. 2015; Pollard et al., 2021).
- Embed prevention and early intervention in public services (Pollard et al., 2021).
- Building capacity of communities to deliver public health services (Hatzidimitriadou et al., 2012).

Mutual Benefits

- Community power can strengthen community wellbeing and resilience (Pollard et al., 2021).
- Improved access of services including minority groups (Hatzidimitriadou et al., 2012).
- Mutual learning (Hatzidimitriadou et al., 2012)
- New improved access to information (Man et al., 2019).
- Stronger relationships (Hatzidimitriadou et al., 2012; Man et al., 2019).
- Stronger leadership and convening skills (Man et al., 2019).
- Greater knowledge and expertise on a particular issue (Man et al., 2019).
- Connect staff and volunteers more closely to the day to day experiences of people (Mind nd).
- Stronger support for innovation and change (Man et al., 2019)

Barriers

What are the barriers to coproduction?

- A problematic organisational culture is a significant barrier (Curvers et al 2016). This may include conflicting agendas and issues of power (Hatzidimitriadou et al., 2012) such as resistance to sharing power and control (Bagnall, South, Jones and Southby, 2024).
- Changing culture is hard, takes time and can be challenging. Avoiding individual burnout is very important. Arnold, Coote, Harrison, Scurrah and Stephens 2018)
- Taking risks challenges everyone (Newton, 2022).
- Governance structures may impede things such as information sharing or harbour strongly held professional beliefs about what is best for the community, or simply unease about adopting a different approach (Bagnall, South, Jones and Southby, 2024).
- Poor quality relationships with communities may hamper progress (Harden, Sheridan, McKeown, Dan-Ogosi and Bagnall, 2015).
- There may be a lack of commitment or reluctance to engage fully from both charities and people with lived experience (Hatzidimitriadou et al., 2012; Bagnall, South, Jones and Southby, 2024)
- Previous 'bad' experiences can linger (Newton, 2022).
- Coproduction done wrong may cause harm (Newton, 2022).
- May be hampered by limited capacity of community organisations (Hatzidimitriadou et al., 2012).
- May be hampered by limited skills of professionals (Hatzidimitriadou et al., 2012) – finding the right people to do the work (Newton, 2022).
- Management of expectations (Hatzidimitriadou et al., 2012).
- People can get stuck (Newton, 2022).
- Management of time and flexibility (Curvers et al 2016; Man et al, 2019).
- Cost (Curvers et al 2016); unpaid overtime, and that stress and burnout (Bagnall et al., 2020).
- Many charities just do not know how to cultivate user voice (Curvers et al., 2016).
- Individuals can overidentify with the organisation and feel that their way of doing things is the only way (Bagnall et al., 2020).
- People may be hard to reach and difficult to gather structured feedback from e.g., users may have cognitive disabilities that make communication hard; or they may be young children (Curvers et al., 2016).
- Practical challenges in 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).
- Technical challenges analysing, visualising and investigating feedback data (Curvers et al., 2016).
- Infrastructure (investing in infrastructure and planning; support, training and capacity building) (Harden et al., 2015).
- A lack of inclusive and accessible practice (Harden et al., 2015; Newton, 2022).
- Finding the right people to do the right work (Newton, 2022).
- It can be difficult to see the difference it makes (Newton, 2022).
- Costs involved e.g., travel expenses, childcare costs (Bagnall, South, Jones and Southby (2024).
- Putting unnecessary requirements on the role descriptions that limit who can take part (Man et al., 2019).
- Make engagement safe and inclusive –equipping everyone with the skills to participate or facilitate fully (Man et al., 2019)
- Differences in organisational culture, attitudes, and practices between participating organisations can pose potential difficulties in multisector collaborations (Bagnall, South, Jones and Southby, 2024).

How to collaborate

Prepare the organisation for lived experience engagement

Set a goal

- Be ambitious but realistic (Lamb, Seifu and Chapman, 2023; Chapman, 2024).
- Understand and set the goal (Homer, 2019); be clear from the start what is hoped for from the engagement (Berks, 2021); have a clear shared purpose (Chapman 2024).
- Ensure lived experience is involved early on – and throughout – decision making (Chapman, 2024).
- Articulate your clear shared purpose, define what you want to achieve (Lamb, Seifu and Chapman, 2023).
- Develop your approach by designing structures, processes and mechanisms that will help you achieve your goals. How will you resource this? What skills does the organisation need? (Lamb, Seifu and Chapman, 2023). Let lived experience influence strategic and operational decisions (Chapman, 2024).
- Clarity and transparency about expectations and plans is essential: e.g., different levels of involvement, the scope of influence for participants, and how decisions will be made (Bagnall, South, Jones and Southby, 2024; Berks 2021; Man et al., 2019).
- Map how you want coproduction to develop it in future; for example, is the intention to scale up the solution, replicate it elsewhere, or make it sustainable in the long term? (Man et al., 2019).

Strategic buy-in

- Build buy-in and excitement (Lamb, Seifu and Chapman, 2023; Bradley, O'Kane and Murtagh 2021; Man et al., 2019).
- Show commitment to centring lived experience from senior leadership down (Chapman, 2024; Homer, 2019), shaping strategic and operational decisions. Questions include: 'how does the type of involvement we choose align with the strategy or the principles behind our approach to centre lived experience?' and 'what level of influence does lived experience need to have?' (Lamb, Seifu and Chapman, 2023; Chapman, 2024).
- Undertake an organisational-wide consultation so that people can explore their thoughts and views and feel more connected to the work when it starts to happen (Newton, 2022).
- Consider what is going on for the organisation that might impact the ability to meaningfully centre lived experience? What is needed to facilitate this? Is there sufficient stability and headspace to pursue this now? (Lamb, Seifu and Chapman, 2023).
- Investing in infrastructure and planning for delivery. Much evidence pertains to how multisector collaboration is funded, emphasising the importance of investing in the 'infrastructures' that support collaboration (e.g., staffing/ capacity, VCSE organisations, community networks and activities, as well as physical infrastructures). (Bagnall, South, Jones and Southby, 2024).
- Consider what governance decisions you want lived experience to influence? What type of involvement is right? To what extent lived experience should influence Board decisions – solutions include:
  - Recruit trustees with lived experience to the Board (it is important that this doesn't feel tokenistic, may need changes to the Board dynamics or culture);
  - A shadow board or advisory panel of people with lived experience that advises the main Board of Trustees (without legal responsibility or decision-making power);
  - Recruiting trustees how have a mixture of lived and learned experience;
  - Where and how might you recruit for new Trustees? What skills are you specifying in the job description? (Lamb, Seifu and Chapman (2023).

Organisational culture

- What is the organisational culture? Where might the culture enable or impede the journey to centre lived experience? What are the organisational values? Will these values support or hold you back in the journey? (Lamb, Seifu and Chapman, 2023). Need a culture of openness and flexibility (Chapman, 2024) and a culture of inclusion (Homer, 2019).
- Consider what was done in the past in relation to involvement or drawing on lived experience, and what has been learnt?
- Where does lived experience currently influence the organisation? How impactful and meaningful was this? Why? (Lamb, Seifu and Chapman, 2023).
- Be willing to do things differently to involve Experts by Experience (Chapman, 2024).
- Value relationships; support everyone to engage (Chapman, 2024; Man et al., 2019).
- Quality of existing relationships – good links and networks, buy in from other VCSOs and community leaders; establish and build on partnerships; address 'poor' relationships (e.g. where there has been tokenistic engagement and antagonism in the past) (Bagnall, South, Jones and Southby, 2024).
- Acknowledge that organisational change is hard and can be unsettling for people, even those who believe that this work is crucial (Newton, 2022).

Organisational skills and resources

- What skills, experience and capacity exists to centre lived experience? (Lamb, Seifu and Chapman, 2023). Consider who you need – what skills and qualities should they have? (Berks, 2021).
- Put continuous learning high on the agenda (Chapman, 2024).
- Acknowledgement of existing capacity and capability within the community and participating organisations – taking action to build capacity where needed (Bagnall, South, Jones and Southby, 2024; Homer, 2019).
- Reflect honestly on resources and capabilities, strengths and needs: what resources or skills are already available? (Lamb, Seifu and Chapman, 2023).
- Use local knowledge (Bagnall, South, Jones and Southby, 2024).
- Accountability and good governance is essential (Bagnall, South, Jones and Southby, 2024; Bradley, O'Kane and Murtagh 2021) alongside regular, open and clear communication (Bagnall, South, Jones and Southby, 2024).
- Take a long-term approach (Bagnall, South, Jones and Southby, 2024).
- Prepare people for the change that is to come. People with lived experience may not speak in the same way as staff and they will ask questions about why things are done in a certain way, as well as offer ideas of how things could be done differently. Some people will feel threatened by this, become defensive, and/or be deeply challenged by the perceptions that they hold about those with lived experience that they were previously unaware of (Newton, 2022).

Learning from others

- Involve experts by experience – consider what level of influence lived experience should have. Be honest about this from the beginning (Lamb, Seifu and Chapman, 2023).
- Set up infrastructure for participation, such as neighbourhood forums, that bring agencies and community members together to develop long-term trusting relationships between and within communities, professionals and organisations (Bagnall, South, Jones and Southby, 2024; Chapman, 2023).
- Learn from other charities, including sector power dynamics and strategy; consider collaboration (Lamb, Seifu and Chapman, 2023).
- Understand what is important to users (Man et al., 2019).
- Try to look at things from different perspectives; challenge assumptions (Man et al., 2019).
- Be mindful that if a group is focused on verbal contributions only, it will exclude those that prefer to, or are more able to, communicate in other ways. Build in different ways for people to communicate so that it is not dominated by those that are articulate, vocal, and confident. For example, you could ask people to contribute individually in advance or through writing, poetry, art, vlog, or graffiti board (Newton, 2022).

Honesty and transparency

- Consider how you will ensure delivery is safe, meaningful and inclusive, including ethical considerations (Lamb, Seifu and Chapman, 2023).
- Be clear with all involved about what can and can't be influenced (Lamb, Seifu and Chapman, 2023).
- Consider diversity – be careful of just picking 'nearest and dearest'. How will you reach out to people? (Berks, 2021).
- Value is often placed on people with lived experience 'having a seat at the table'. Whilst that is important in many situations, it's also important to interrogate the table as sometimes it simply isn't big enough, isn't welcoming enough or stifles people. The table may need to be dismantled and rebuilt. (Newton, 2022).

Adequate funding

- Build a budget that accurately reflects the work that is needed (Bagnall, South, Jones and Southby, 2024). Whether this is remuneration for time, provision of refreshments, or costs of hiring a room that people will feel comfortable in, it needs to be accounted and planned for. Otherwise, it may not be able to achieve what it is intended. This will feel like failure despite the best of intentions (Newton, 2022).

Delivering lived experience

Strategic and operational decisions

- Ensure Lived experience is shared early and influences strategic and operational decisions (Lamb, Seifu and Chapman, 2023; Chapman, 2024).
- Create the conditions so that people are in environments where they can grow, learn, thrive, and be valued in as safe a way as possible. This takes strong organisational leadership and a culture that values people for who they are and takes the time to develop relationships that lead to creating better futures together (Newton, 2022).
- Have a plan in place and communicate that with everybody so they know what's happening, when, and why. This helps everyone feel more included, even if it's not something that they will be doing individually or directly. Induction and onboarding are inclusive of progression pathways and sets out expected ways of working, and indicative timeframes, so that people have clear information and guidance about ways of working. (Newton, 2022).
- Start at a scale and pace that works for your organisation and in a way that you can learn as you go (Newton, 2022).
- Be clear on what is in scope and what is out of scope, what's possible and what's not possible so that you don't make any false promises or unintended false promises that lead to disappointment, disillusionment, and anger (Newton, 2022).
- Continuous learning and improvement are high on the agenda (Lamb, Seifu and Chapman 2023).
- Senior leaders should:
  - Set clear expectations around how certain situations will be navigated;
  - Be clear about the principles and values that should underpin the delivery of involvement work;
  - Support colleagues to make decisions that result in meaningful and safe delivery or involvement work (Lamb, Seifu and Chapman, 2023).

Ways of working

- Develop processes that bring people into the work regularly, as well as enable them to leave, ensuring that this is well advertised, communicated, supported, and celebrated. Focus on learning from each other, welcoming diversity of thought and experience, and be intentional in not making assumptions about other people's lived experiences (Newton, 2022).
- Be clear that doing this work isn't for everybody and don't shy away from having difficult conversations about the potential impact it can have and how people can be supported (Newton, 2022).
- Don't assume that people are experienced in being in a group or a meeting. Provide an induction, one-to-one, or briefing session ahead of people's introduction to a group setting so that there is a clear understanding of the group, everybody's role within it, and how they can contribute. (Newton, 2022).
- Develop group agreements, charters, codes of conduct, and terms of reference so that everybody understands what any specific group is there for, the terms for engagement, and expected ways of working or behaving. This can be a standalone document that is used throughout an organisation, or established every time a group of people comes together to undertake a specific piece of work. (Newton, 2022).
- Create opportunities for people to engage (Homer, 2019).
- Joint decision making (Bagnall, South, Jones and Southby, 2024).
- Identify risks and design around them (Man et al., 2019).
- Incorporate the input of lived experience in your work (Berks, 2021).
- Personal development plans that log somebody's work and the outcome of a project they were involved in can help people see for themselves that their lived experience has made a difference (Newton, 2022).

Boundaries

- Boundaries are required to ensure that the purpose and outcomes of coproduction activities are clear, and within these boundaries, creativity is encouraged to achieve these outcomes (Bradley, O'Kane and Murtagh 2021).

Relationship building

- The importance of trust and relationship building is crucial. Be honest and transparent about the role of lived experience (Lamb, Seifu and Chapman, 2023): relationships take time to build (Newton, 2022).
- Need to invest time, effort and resources into building relationships and trust between agencies wishing to engage with communities, and the communities themselves, especially those with difficult past relationships or conflicts with other agencies (Bagnall, South, Jones and Southby, 2024).

Clear communication

- Present information in readily accessible ways and avoid overuse of jargon (Bradley, O'Kane and Murtagh 2021).

Training

- Training in co-production and community engagement for both organisational staff and for community members is important (Bagnall, South, Jones and Southby, 2024); listening and communications skills are vital (Newton, 2022) – training in 'soft' communication skills for staff (Bagnall, South, Jones and Southby, 2024).
- The people you are trying to influence need to be supported and/or trained in how to best work with people's lived experience (Newton, 2022).
- Think about where participants may be able to take on new roles to develop skills or contribute beyond their "day job" (Man et al., 2019).

Timeframes

- Be clear on the process and deadlines (Berks, 2021).
- Set clear expectations around the time to develop and implement the approach (Lamb, Seifu and Chapman, 2023).
- Provide people with opportunities to grow and develop their skills within clear timeframes based on the organisation's requirements as well as people's aspirations for their future (Newton, 2022).
- Important to make time for mentoring and other support for community members is important, enabling an equal voice within decision-making bodies (in other words, to sit at the 'top table of decision making') (Bagnall, South, Jones and Southby, 2024).

Resources

- Ensure sufficient financial and time resources (Lamb, Seifu and Chapman, 2023).
- Allow sufficient time for the process (Bradley, O'Kane and Murtagh 2021).
- Time spent building relationships and trust with experts by experience is crucial (Lamb, Seifu and Chapman, 2023).
- Additional time may be needed to make decisions (Lamb, Seifu and Chapman, 2023).
- Time spent on activities (time and cost to run a co-design workshop or consultation) needs to be considered from the beginning (Berks, 2021).
- Time and resources needed to support engagement (prepare and debrief from activities, meetings or decision making forums ensures everyone can engage fully – might need to factor in training or additional resources to support a person to engage (Lamb, Seifu and Chapman, 2023; Newton 2022).
- Other costs should be considered (hiring a space, expenses like childcare) (Lamb, Seifu and Chapman, 2023).
- Ensure that you can match decisions with sufficient resources. If you can't, scale it back so it is more realistic (Lamb, Seifu and Chapman, 2023).

Organisational culture

- Value both community knowledge and professional expertise (Bradley, O'Kane and Murtagh 2021).
- There is a culture of openness and flexibility (Lamb, Seifu and Chapman, 2023).
- Common ground, shared language and understanding (Bagnall, South, Jones and Southby, 2024).
- Be clear about how decisions on the approach will be made and by who. Set clear lines of accountability and responsibility for each activity and decision (Lamb, Seifu and Chapman, 2023) If a group has decision-making responsibilities within it, be clear about how decisions are made and who has the final say to manage expectations (Newton, 2022).
- Listen to feedback from colleagues about what is working and not working, either in the design or delivery of your approach, and commit to responding to it (Lamb, Seifu and Chapman, 2023).
- Address challenges as they occur rather than leaving them to fester and become even bigger over time, particularly if this is with a group that meets on a regular or ongoing basis (Newton, 2022).
- Create processes that enable you to take time to regularly reflect on what has worked, what hasn't, and what you would do differently in the future and why (Newton, 2022).
- Feedback loops on the progress that is being made, even if the feedback is that 'no progress has been made, and this is the reason why' is essential but it often gets forgotten amongst everything else. (Newton, 2022).
- Teamwork when developing options and taking decisions, openness to all ideas and discussion genuine communication across all partners, honesty in sharing information and views (Bradley, O'Kane and Murtagh 2021).
- Work in collaboration with organisations that are experts in this work and ask them to hold you to account for your practice, as well as seek their advice on how to do things differently and better (Newton, 2022).
- Be proactive in seeking feedback about what works and what doesn't, and then be willing and able to change this and adapt (Newton, 2022).
- Intentionally recruit people that look like, speak like, and act like the communities that you are trying to reach (Newton, 2022).

Ethical considerations

- Organisations should consider the risks that people may face when they use their lived experience in very public settings, such as on social media, and the potential consequences of this in the digital age we are living in, and have robust ways of working in this regard. This is valuable to everybody though, not just those with lived experience (Newton, 2022).
- Be honest and don't sugarcoat it when things go wrong – help people feel safe to say what they think when things don't go to plan, and to challenge constructively when it's not been good enough. This requires honest and trusting relationships between people. (Newton, 2022).
- Understand your unconscious bias so that you can change your working practices (Newton, 2022).

Trauma informed

- Trauma informed approach/practice is required to prevent further harm or re-traumatisation or triggering of distress, Safeguarding, and strengths-based practice (Newton, 2022), to recognise and value the unique capacity, skills and perspectives of others (Lamb, Seifu and Chapman, 2023).
- Underpin everything in a trauma-informed way and ensure that teams are trained within this way of working (Newton, 2022).
- Ensure easy access to reflective practice to support people to process and understand what this work means to them on a deeper emotional level. Whilst not everybody will want to do that, the offer needs to be made (Newton, 2022).
- Acknowledge that you can never make this work truly safe for anybody. There will always be triggers for people within it but you can do your best to create as safe a space as possible so that people can bring their whole selves, including all of their different identities, into it (Newton, 2022).
- Ask people what they think are the risks they will face doing this work, and how they can be best supported to manage them. Don't assume that people are too vulnerable to use their lived experience – put them in the driving seat, and let them decide (Newton, 2022).
- Don't ask for people to tell their story as a stand-alone activity in and of itself – spend time helping people think about what has happened to them and what they want others to learn from this, in addition to what they feel uncomfortable or unable to share with others (Newton, 2022). Story-telling can elicit powerful emotional responses. But that doesn't mean that things change as a result. Clearer links between what somebody is able to share about their lived experience and how this can lead to change is required (Newton, 2022).
- Be able to spot when vicarious trauma is happening. Have a robust policy and process in place to be able to deal with this scenario (Newton, 2022).
- Don't make assumptions that the work is causing harm based on people's behaviour and words. Check this out with them in more detail and enable them to decide whether or not it's for them, and how the organisation can work differently to enable them to be heard with respect and dignity. (Newton, 2022).
- Help people move away from the work, and stay away from it, in a dignified way if it causes them harm. For some, this might mean a break from it or access to more support, but for others, it may mean indefinitely. However, it should be noted that this is more difficult for people when their financial security is at stake. On these occasions, exit routes are to be carefully planned and managed, bearing in mind employment legislation (Newton, 2022).

Confidentiality

- Confidentiality where appropriate (Bradley, O'Kane and Murtagh 2021). How will you ensure that experts by experience have the privacy and anonymity they want while sharing their stories, expertise, insight or making decisions? Consent to take part. Not feeling pressured or hurried into involvement (Lamb, Seifu and Chapman, 2023).
- Feedback loops established so everyone will be able to hear about the impact they had on decision or delivery (Lamb, Seifu and Chapman, 2023).

Psychological safety

- Create spaces that are as psychologically safe as possible for people. This may mean separate spaces for the most difficult or controversial topics to enable people to express themselves and feel heard without fear of a backlash or judgement from those that may have opposing views (Newton, 2022).

Support mechanisms

- Put in place a range of support mechanisms that everybody can access. This might include regular support and/or supervision sessions as well as access to counselling, mentoring, telephone support, online support, wellbeing days, or a well-being fund (Newton 2022). Establish a buddy system, mentor, or a coach that can ease people into groups if this is something that they are not used to or want to become more confident within (Newton, 2022).

Previous bad experiences

- Acknowledge that the emotional pain that people have felt as a result of the social injustices they have experienced can make people feel angry can make other people feel uncomfortable and/or triggered. Previous 'bad' experiences can linger if they're not addressed (Newton, 2022).
- Help people that are working with and alongside people with lived experience to understand and appreciate that people communicate their insight in a variety of ways, all of which are valid. Some people may express extreme anger and frustration within this work, but their words and behaviour should not be dismissed, and they should not be excluded for not communicating in the way that others do (Newton, 2022).
- Be mindful that risk assessments feel clinical and introducing a risk assessment can feel like a clinical intervention that disempowers people. (Newton, 2022).

Own lived experience

- Appreciate that people within the workforce may also have their own relevant lived experience and this may cause tensions that need to be worked through. Does their lived experience count, or does it not? Are they expected to utilise this in the future, or is this something that is not required? It's important for people to individually chose whether or not they disclose their lived experience and for that to be treated confidentially and respectfully as they choose (Newton, 2022).

Inclusion

- Consideration should be given to gender, class, race, age, and disability, in addition to the specific lived experience that brings people together (Newton, 2022).
- Accept people for who they are and welcome them with open arms. However, be aware that this approach may only work with those that feel most comfortable with you and are likely to already feel accepted, rather than everybody (Newton, 2022).
- Understand structural racism, and how this manifests within the charity sector - call it out within your organisation and be proactive in addressing it so that people can see, feel and hear it so that it can be addressed (Newton, 2022).

Ensuring accessibility

- Removing barriers to entry (e.g. travel costs, childcare, language, confidence). Are you putting unnecessary requirements on the role descriptions that limit who can take part? Be more flexible in how people input or engage. Make engagement inclusive – how will you equip everyone with the skills to participate or facilitate fully so that you hear from everyone? How will you make spaces as safe and inclusive as possible? Can you partner with others to support you? (Man et al., 2019).
- Consider the time, location, and duration of groups so that they work for the people that you want to come to them, rather than what works best for the organisation (Newton, 2022).
- Provision by organisations of appropriate accessible meeting spaces (Bagnall, South, Jones and Southby, 2024).
- Ensure that any meetings or events, including social events, are held in physically accessible buildings (Newton, 2022).
- Co-location in shared physical space (Bagnall, South, Jones and Southby, 2024). Creating a safe space appeared to challenge normative power dynamics. This sometimes meant that VCSE organisations' premises could be used as neutral meeting spaces in order to facilitate dialogue between service users and statutory agencies (Bradley, O'Kane and Murtagh 2021).
- Flexibility/revision to training schedules and materials – planned training materials may not suit community members' literacy levels or learning styles, and scheduled training may clash with caring responsibilities or cultural or religious observances. In organisations, staff time needs to be protected for training and engagement as other priorities arise (Bagnall, South, Jones and Southby, 2024).
- Design meetings with people in mind – physically accessible and at convenient times (Homer, 2019).
- Come to meetings prepared to participate, having read and considered papers in advance. Good meeting facilitation practices (Bradley, O'Kane and Murtagh 2021).
- Compensate participation related expenses (mitigate financial barriers to participation) (Homer, 2019).
- Check your co-design approaches against the initial capabilities and interests of the participants, are they achievable? (Man et al., 2019).
- Actively challenge people when they speak or act in a discriminatory way and ensure that any group agreements, codes of conduct, or ground rules enable action to be taken when required. These should be supported by policies and procedures (Newton, 2022).
- Spend time understanding the broad range of micro-aggressions that people from Black and brown communities face daily so that you can prevent yourself and others from unintentionally committing these micro-aggressions yourself. This can also be applied to the micro-aggressions that are experienced by people with disabilities and members of the LGBTQ+ community (Newton, 2022).
- Provide awareness training sessions (ideally those that have been designed and are led by people from different and diverse communities) to enable people to better understand different identities and dispel any myths or stereotypes that may exist (Newton, 2022).
- Take the time to think about what makes an inclusive and accessible place of work and how that would feel for those that are not the majority, dominant group. What do people need to feel included and how can that be put in place? (Newton, 2022).
- Understand that you don't need to know everything about a specific community of people, but you do need to have an awareness and competency around issues of authenticity and be able to acknowledge and infer messages so that people know you understand and work against oppression (Newton, 2022).

Facilitating meetings

- Using qualified mediators or highly experienced facilitators (internally or externally sourced) with really good communication skills, including listening skills (Newton, 2022).
- Intentionally giving people uninterrupted time to speak (Newton, 2022).
- Spend time talking through and agreeing on how a breach of agreed ways of working will be handled and make sure everybody is clear on that, and then stick to it (Newton, 2022).
- Call time out if things get difficult, and on rare occasions, bring the conversation to a close (Newton, 2022).
- Actively not be defensive and support others to do the same – if you're asking for people's opinions you need to be able to listen to them, understand them and then act on them – not ask for the sake of asking (Newton, 2022).
- The ability and confidence to point out when somebody's behaviour is not acceptable and work with them to manage this in the future (Newton, 2022).
- Ensure the right people are in the room to have the conversation and there is a common goal that you're all working towards (Newton, 2022).
- Put in place support before and after the most difficult conversations so people aren't left with a set of raw emotions and nowhere to go with them (Newton, 2022).
- Appreciate that some people behave or communicate in a way that may be deemed unacceptable but comes from a place of anger and hurt about their experiences in life, how they have been failed by others, and the fear of that happening again within this space (Newton, 2022).
- Spend dedicated time with those people who are less likely to speak and work with them to understand how their views and opinions can be shared in different ways that work better for them e.g. through poetry, voice notes, writing, and artwork (Newton, 2022).
- Acknowledge that there are some spaces where there will always be opposing views and that those coming into this space are aware of that and are supported and equipped to take part in those discussions. This was particularly apparent when people spoke about domestic abuse, suicide, and recovery (Newton, 2022)/
- Learn not to make assumptions about any one person and continue to be open to learning from people (Newton, 2022).
- Restorative and reflective practice enables people to understand themselves and each other (Newton, 2022).

At the end of the project

- After people have given their time and knowledge, it is important they still feel involved if they want to be. Ensure you communicate the changes made and that exit and development strategies are created for users who want to continue engaging with the work. (Man et al., 2019). Celebrating the end of projects and the difference that it has made helps everybody understand and be able to remember what has been achieved (Newton, 2022).
- the reality of this work is that sometimes people's lived experience does not achieve the intended change that is needed or required. The systems that this work exists in are complex and managing people's expectations of what can be achieved, as well as what can't be achieved, is important (Newton, 2022).
- Deliberately asking who is not in the room at the beginning of every project, then working out strategies to bring them into the room. This may include doing the work completely differently, setting up different spaces, going directly into communities where people are most comfortable or working with community leaders (Newton, 2022).

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