St Giles

Turning a past into a future

Engaging with Experts by Experience Toolkit

March 2026

Preface

from the Experts by Experience at St Giles Trust

Many of us who contributed to this toolkit became Experts by Experience because of our lived experiences of domestic abuse and/or sexual violence, and because we wanted to use those experiences for good—to help shape organisations and services for the better. In becoming Experts by Experience, we also challenge the stereotypes that assume people who have lived through trauma will forever be broken, traumatised, or incapable of recovering and living full lives. We have faced these assumptions in policy spaces, in health and social care, in the criminal justice system, and in many other settings. Yet we do recover.

Many of us go on to study, upskill, retrain, work in a range of roles, and support others who are going through what we once did. When we step into this role as Experts by Experience, we are not stories to be extracted but expertise to be valued. We hold knowledge and understanding that cannot be learned solely through training or study, and we believe this gives the work greater authenticity.

Too often, however, the voices of those who have lived through harm are invited into professional spaces without the support structures or trauma awareness needed to make involvement safe, meaningful, and equitable. These spaces can retraumatise, tokenise, or exhaust the very people practitioners seek to learn from. Being asked to share personal experiences without clarity, boundaries, support, or fair recognition can reinforce power imbalances. This toolkit is needed to bridge that gap.

Overall, we want this toolkit to strengthen engagement practice with Experts by Experience. When organisations genuinely listen to and respond to those with lived experience, services become more effective, compassionate, and accountable. We want disclosures to be safe, support to be holistic, and outcomes to improve for everyone involved. And we want others to know that there is life beyond what they have been through or are going through. Becoming an Expert by Experience can be a powerful part of that journey.

Preface

from Frances Newell, Assistant Director, NHS England Domestic Abuse and Sexual Violence Programme

People who have experienced domestic abuse or sexual violence have essential skills and perspectives to bring as we work to improve the NHS response in this area, helping us to understand where we need to do better or change what we do. People with lived experience spot opportunities to make services safer and more efficient and improve access for groups who face particular barriers in getting the health and care they need. The Experts by Experience supported by St Giles Trust have enabled us to keep a strong focus on patients and service users in everything we do and have taught staff on the programme a huge amount.

It's always important when we work with people with lived experience that we do so in a meaningful, supportive and respectful way. In the area of domestic abuse and sexual violence we need to think carefully about creating safe spaces for everyone to contribute.

This toolkit is full of practical information that can support colleagues across health and care to work well with people with lived experience of domestic abuse and sexual violence. That includes working with NHS staff who themselves can be victims and survivors of these crimes.

It has been a pleasure to work with St Giles Trust and the Experts by Experience, and I really welcome this resource. Thank you to the authors for their hard work on bringing it together and for everything they have done to contribute to the programme so far.

CONTENTS

GLOSSARY

Supervision: A confidential, structured meeting with a supervisor to reflect on practice, manage risk and support wellbeing.

Emotional Readiness: The extent to which a person feels psychologically prepared and resourced to engage with an experience or change (e.g. disclosure, support, therapy, training), including having enough safety, stability, and coping capacity to manage the likely emotions without becoming overwhelmed.

Experts by Experience: People who use their lived experience of an issue or service and what they have learned from it, to inform, improve, or shape practice, policy, training, research or service design.

Intersectionality: A framework for understanding how overlapping aspects of identity and social position (e.g. race, gender, disability, sexuality, class) combine to shape a person's experiences, including access to power, resources, discrimination and outcomes.

Trauma: A response to overwhelming or threatening experiences that exceed a person's ability to cope.

Trauma- Informed Approach: A way of working that recognises how common trauma is, how it can affect people, and that prioritises physical and emotional safety, trust, choice, collaboration, and empowerment, while aiming to avoid re-traumatisation.

Vicarious Trauma: The cumulative impact on a person's wellbeing and worldview caused by repeated exposure to other people's trauma through their work or role, which can affect emotions, thoughts, and sense of safety even though the trauma was not experienced directly.

1. INTRODUCTION

This toolkit was developed by a team of existing Experts by Experience in a partnership project between the NHS England Domestic Abuse and Sexual Violence Programme Team and St Giles Trust. **Experts by Experience** are people who use their lived experience of an issue or service and what they have learned from it, to inform, improve, or shape practice, policy, training, research or service design. The aim of the project was to ensure that NHS England's work on domestic abuse and sexual violence considers the insights of people who have experienced abuse and violence in its planning, policy development and improvement activities.

Following two and a half years of the Experts by Experience project, the current team has come together to produce a toolkit for NHS colleagues and the Department for Health and Social Care teams, seeking to work with people with lived experience, both patients/service users and NHS employees. However, we believe this toolkit is applicable for other organisations who aim to integrate lived experience into their work. The aim of the toolkit is to:

- Identify and share practical recommendations for good practice when engaging Experts by Experience
- Communicate a trauma-informed approach to working with Experts by Experience.
- Offer resources, activities and self-reflection exercises that support facilitators and/or organisers looking to engage with Experts by Experience.

This toolkit was developed through a series of four workshops exploring themes and questions around engaging Experts by Experience and co-written by the team. Due to the context of the project, this toolkit is written from the perspective of engaging with Experts by Experience with lived experiences of domestic abuse and/or sexual violence but could be adapted to other lived experience contexts where trauma-informed approaches are vital.

It is organised into four sections, beginning with the core principles of trauma-informed practice and intersectionality. It then moves into considerations for practitioners when planning an engagement, including setting up an engagement and recruiting Experts by Experience. Building on this, the next section focuses on the engagement itself, offering guidance on facilitation and practical advice on preparing the space. The final section outlines practical ways to conclude engagements in trauma-informed and supportive ways.

Meaningful engagement with Experts by Experience requires a reorientation of power on how we understand expertise and engagement. This requires time, effort, and a consistent practice to develop safe and empowering engagements. This toolkit is not a check-list exercise, or a prescription for "how to do" engagements, but rather a space where practitioners can reflect on their practices before engaging. By the end of the toolkit, we expect that practitioners:

- Understand the benefits of working with Experts by Experience, whether patients/service users or staff members.
- Feel confident in how to work with Experts by Experience.
- Understand trauma-informed practice in the context of engagement with Experts by Experience.

1.1. Why Experts by Experience?

People who have lived through domestic abuse and/or sexual violence (as well as many other first-hand experiences of social issues and challenges) are in the strongest position to speak about the issues that affect them, offering valuable firsthand insight into which support systems are effective and which fall short[i]. Working with Experts by Experience ensures that services are designed to fully meet the needs of those you access them. Experts by Experience voices "should be recognised as essential evidence in its own right"[ii].

In the context of the NHS, engaging with Experts by Experience is a critical part of delivering NHS services. As the National Health Service Act 2006[iii] states, NHS England has a legal duty to involve the public in decisions about how its commissioned services are planned, changed and run. NHS England's policy on working with people and communities sets the expectation that involvement happens across all aspects of NHS England's work, including policy and strategy development.

How does lived experience benefit the NHS?	
Understanding of real-world Impact	Experts by Experience can highlight practical barriers, gaps, or challenges that policymakers might not anticipate. First-hand accounts showing how systems *work* in everyday life, beyond statistics.
Improving accessibility & relevance	By involving Experts by Experience, NHS policies are more likely to use language, pathways, and support structures that resonate with those who use these services, avoiding a "top down" approach.
Effectively identifying inequities	Experts by Experience can identify inequalities in access, quality, and outcomes sooner than data alone. Their insights can address inequalities rather than unintentionally worsening them.
Legitimacy and trust	When patients/clients see that NHS policies are shaped by people like them, it builds trust and a sense of ownership. This makes policies easier to implement, because they feel less imposed and more co-created.
Innovation and new perspectives	Lived experience can challenge assumptions and bring fresh ideas about what works, often suggesting low-cost or practical solutions that professionals might overlook, adding creativity to problem-solving.

Examples of work that Experts by Experience have been involved with:

Lived Experience Work	Examples
Research & Service Directories	**Compiled Service Directories for the NHS** – providing structured listings of active services across England exploring Domestic abuse/Sexual Violence support for key demographics (male survivors, young people, LGBTQ+, Housing, & Mental Health).
Video Diaries Q & A	**Narration of personal video diaries for the NHS England Domestic Abuse and Sexual Violence Team -** discussing their experiences of accessing NHS provision when they were in abusive relationships. These diaries focused on best practice & changes they would hope to see for others in future.
Bespoke Training Packages	**Co-production with training provider (Lisa Ward Consultancy Ltd)** to create bespoke training packages for the NHS, creating in person as well as a self-guided learning tool exploring Lived Experience work, Trauma Informed Practice & Intersectionality.
Mandating Sexual Misconduct Training	**Working group** reviewing the NHS business case for Mandating Sexual Misconduct training for all NHS staff.
General Practice Working Group	**Discussions around General Practice responses** to survivors of Domestic Violence & Sexual Violence, highlighting a greater need for training in spotting the signs as well as language used to encourage open discussions "do you feel safe? What does safe mean to you?
Multi Agency Meetings	**Representation on various multi agency groups** – Expert Advisory Group, Programme Oversight Group, Sexual Safety Group
Policy Review	**Provided insight** & recommend amendments to the Sexual misconduct Policy & campaign, paying attention to detail, rearranging priority areas, use of language, improving reputable service links.
End of Year Report	**Co-produced an end-of-year report** detailing the work completed by the team & next steps.
Language Matters Focus Group	Attended and contributed to five Language Matters focus groups looking at how language can be used/avoiding stereotypes

1.2. Who are the Experts by Experience?

"Tapping into this wealth of experiences can be a healing and empowering experience."[iv]

Experts by Experience come from a range of different backgrounds, professions, ages, ethnicities, income levels, educational levels, and more. As highlighted by Imkaan and Women's Aid (2024)[v], the term 'expert by experience' recognises individuals and that they have an expertise which needs to be at the centre of conversations.

Having direct experience of a service, policy or system means they hold detailed and practical knowledge of how services operate. This depth of understanding can highlight patterns, gaps, opportunities, strengths and improve the impact of work as opposed to solely sharing disclosures of experiences. Moving towards more collaborative approaches through engagements draws out these invaluable insights.

Although some Experts by Experience may offer their service in an informal or voluntary capacity, it is skilled work deserving of renumeration and boundaries. Experts by Experience is not one dimensional but involves a multi-identity expertise (facilitator, analyst, advisor, leader).

1.3. About St Giles Trust

St Giles is a national charity using real-life past experiences to provide advice, training, and support to people facing challenges today. The people we work with come from different backgrounds, situations, and ages. Our approach is not one-size-fits-all. We work with each person as an individual, helping them realise their future goals.

Our skills and experience of engaging with Experts by Experience have been developed over 60+ years of direct service delivery, partnership working, and embedding lived experience, to enhance our own services.

Peer-led services are at the heart of St Giles Trust – we understand that past experiences can inspire & enable people to make positive changes to their own lives, the lives of others, their local communities and wider society. Including lived experience voices from workforce planning stages to training & service design adds unique value to patient care and safeguarding.

2. CORE PRINCIPLES FOR ENGAGEMENT

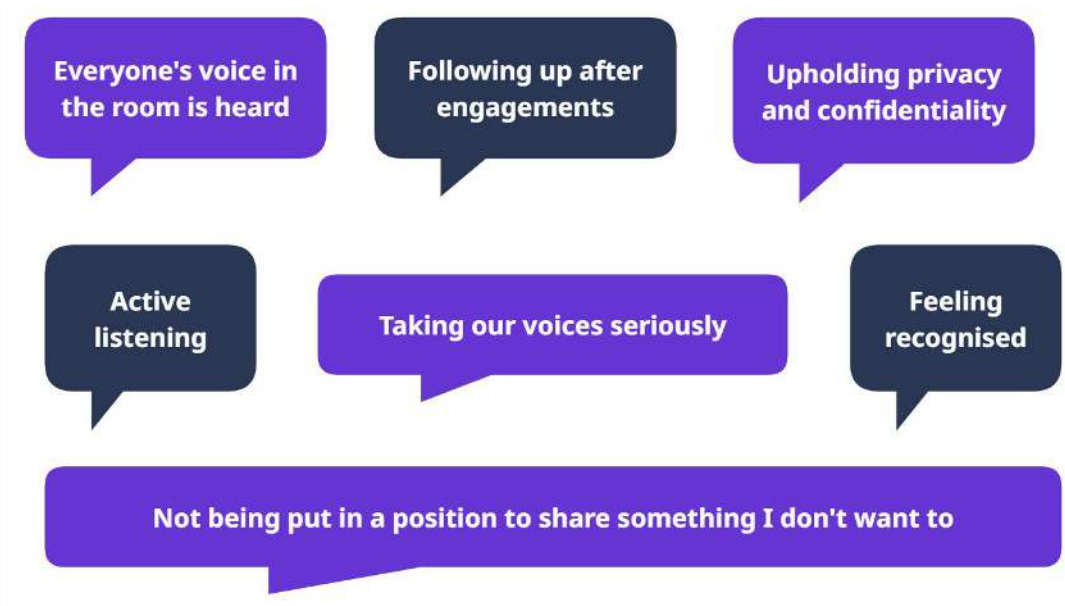
This section outlines the core principles that underpin meaningful engagement with Experts by Experience. When working with people who bring lived experience, having clear guiding principles becomes even more essential. Here, we introduce trauma and intersectionality and explore how both can shape how an individual participates in engagement. Understanding these influences is key to creating trauma-informed spaces that are safe, accessible, and genuinely inclusive.

2.1. What is 'engagement'?

Engagement refers to interactions where practitioners seek to incorporate stakeholders' perspectives at different stages of a project. This can include planning, policy and strategy developments, and the design and/or delivery of improvements to services[vi].

Engagement activities sit on a spectrum that reflects varying levels of involvement and influence (See appendix A). Stakeholders, such as Experts by Experience, may be informed about decisions, consulted on specific elements, or involved as equal partners shaping the process and outcomes. The appropriate level of engagement will depend on the context, objectives, approach, and the lived experience group involved[vii].

When carried out thoughtfully and safely, engagement can be a positive and meaningful experience for participants, helping them feel that their contributions matter. For us, meaningful engagement looks like:



As highlighted by our thoughts, meaningful engagement happens at every stage of the process. When working with people who bring lived experience, how practitioners engage is just as important as the engagement itself. Practitioners need to intentionally develop and reflect on their methods, building approaches that are trauma-informed, compassionate, and responsive. There is no checklist that guarantees good practice; it requires sensitivity, care, and an understanding of how trauma and wider systems shape participation.

(See Appendix A for further information about effective engagement and further reading)

2.2. Understanding trauma

The Office for Health Improvement & Disparities website defines trauma as:

"An event, series of events, or set of circumstances that is experienced by an individual as harmful or life threatening. While unique to the individual, generally the experience of trauma can cause lasting adverse effects, limiting the ability to function and achieve mental, physical, social, emotional or spiritual well-being." [viii]

Trauma affects people in complex and individual ways, understanding that many people may have not only experienced trauma in their personal lives (i.e. through domestic abuse) but also while they interact with institutions (i.e. healthcare and police).

People may experience different forms of trauma, arising in different ways and at different points in their lives[ix]. Two types are particularly important to understand in the context of engagement work, as they may surface in response to activities.

- Secondary trauma refers to the immediate emotional impact that can occur after hearing about or witnessing someone else's traumatic or distressing experience.
- Vicarious trauma describes the gradual, cumulative change in a person's worldview that can develop after repeated exposure to others' trauma in a professional setting[x].

As a result, individuals can experience trauma-related symptoms themselves, such as intrusive thoughts or images connected to what they have seen or heard.

As a practitioner it is important to be aware that other members in the room may experience secondary trauma from exposure to other Expert by Experience's stories, but also that you could be affected by vicarious trauma from repeated exposure to these throughout engagements.

2.2.1. Impacts of traumatic events

The impacts of trauma can emerge through emotional and cognitive signs and symptoms such as shame, dissociation, hypervigilance, hypersensitivity, restlessness, anger, and poor concentration[xi]. This can lead to chronic stress, anxiety and depression.

Besides the more cognitive impacts of trauma, one must also understand it's wider intersecting impact with the broader social, political, and economic context in which it happens[xii]. For many people after experiencing traumatic events, particularly domestic abuse and sexual violence, they may have to work to 'rebuild' their lives which may take years, having a knock-on effect on many aspects of their lives, such as:

- Securing housing and stability — finding a new tenancy or a new school for children, often made harder by housing shortages, rising living costs, or economic downturns.
- Re-entering the workforce — seeking a new job or even a new industry. Abuse may create gaps in employment history.

- Recovering financially — trying to rebuild savings, repair credit scores, or regain financial independence, especially after experiencing economic abuse.
- Managing coping mechanisms — addressing alcohol or substance dependency that may have developed to cope with trauma.

Through this, individuals may reach out to support services such as counselling, housing support, civic injunctions, and financial support. Each Expert by Experience has their own journey through the effects of abuse.

Below are some quotes from Experts by Experience that show how important support from others is, and how services are as part of the healing process.

'Speaking with others and receiving that support and understanding was pivotal to my recovery.'

‘Life goes on but we can be so busy with things that old habits continue. Finding a good counsellor has made a huge difference.’

‘A wonderful nurse used ‘flash back’ therapy where I didn’t have to talk about what happened, but we looked at the anxiety instead and ‘threw it away’.

Over the years, it can be difficult getting through everyday tasks when traumatic memories continue to surface. For many people, trauma becomes intertwined with everyday life. It’s something you can’t fully avoid being reminded of, coming up unexpectedly – sometimes during engagements. Many people with lived experience of domestic abuse and sexual violence develop coping strategies that help them function day-to-day, which can make the ongoing impact of trauma less visible to others.

‘We never lived together. Years later, I’m living alone and he’s still there in the back of my mind.’

‘I lock the bathroom door even though I’m alone in the house.’

‘Wearing extra clothes for bed on nights when I feel uncomfortable has helped me to sleep.’

‘Years later, I still walk around my house to make sure the windows and doors are locked because he used to stand outside, looking in.’

Healing from trauma is a process, where everyone goes at their own pace. Practitioners should not assume that Experts by Experience are ever fully healed from trauma.

2.2.2. The importance of hope

Hope is the belief that something positive can happen. It may be a general sense of possibility or a wish for something good to occur at a particular moment or event. Hope can provide motivation and strength, helping people keep moving forward.

It can be vital to have something positive to move toward when healing after trauma. Becoming an Expert by Experience can play an important role in this process, offering grounding, opening new opportunities,

and helping to sustain hope. It can also create space for positive change by giving people a meaningful way to use their experiences.

2.2.3. Why understanding trauma is important in engagements

Working in areas involving traumatic experiences can increase risks to safety and affect people's wellbeing[xiii]. Trauma shapes how people engage, and sharing personal experiences can also have an emotional impact. Understanding the wide-ranging effects of trauma can help practitioners to reduce harm, recognise signs of distress, and reduce barriers to participation[xiv].

One of the main concerns in engagement work is the risk of re-traumatisation, which can occur when someone is prompted to relive aspects of their trauma without adequate support. Practitioners cannot fully predict what may trigger an individual, but a safe, compassionate, and respectful environment reduces the likelihood of harm. Therefore, trauma-informed practices become vital.

2.3. An introduction to trauma-informed practice

This section draws on the Substance Abuse and Mental Health Services Administrations' (2014) [xv] guidance that outlines that trauma-informed practice is an approach that involves incorporating an awareness of trauma and its impact into the work practitioners do.

***How* we engage people matters just as much as *what* we engage people about.**

2.3.1. The Six Principles of Trauma-informed Practice

The Six Principles of Trauma-Informed Practice offer a practical guide we can use to create engagements that feel safer, more supportive, and that draw on the wealth of knowledge participants bring[xvi]. These include safety, trust & transparency, choice, collaboration, empowerment, and inclusion. They can create the conditions that will enable practitioners to tap into participants' rich knowledge and lived experience.

1. Safety
Create an environment where people feel protected and safe from harm, physically, emotionally and psychologically.
People are more likely to engage when they feel both physically and emotionally safe to do so. Safety can mean different things to different individuals, so allowing people to express what they need is important. In engagements we want participants to feel free from judgment, safe to voice concerns and have their boundaries respected.

Activity: Think of a time when you raised concerns or complaints about something or chose not to. What made you feel comfortable to do so, or alternatively what made you feel uncomfortable to do so? How might you apply this to an engagement?

What's the difference between physical, emotional and psychological safety?

We often think of safety as just the absence of physical harm, but safety goes beyond that, encompassing emotional and psychological dimensions. Each plays a unique role in creating an environment where people can thrive, speak up, and engage fully without fear. This section will now expand on the key forms of safety and what they mean in practice.

Physical Safety: Protection from harm or injury, with environments that are free from threats, violence or dangers, and provide access to necessary resources.

Emotional Safety: Feeling accepted and respected. People can trust what is said and feel their words are heard. It is the sense of feeling embraced for who you are and able to express what you feel.

Psychological Safety: Dr. Amy Edmondson, professor of Leadership and Management at the Harvard Business School, describes psychological safety in the workplace as the 'belief that one will not be punished or humiliated for speaking up with ideas, questions, concerns or mistakes [and]...the team is safe for interpersonal risk taking'[xvii].

Activity: Read the sentences below and spot where there might be a lack of psychological or emotional safety. Identify the sentence that is not an example of psychological or emotional safety risks. Turn the page upside down to see the answers.

1. "The facilitator pushed back on me quite a bit when I raised concerns about the policies. I try to avoid that topic now."
2. "It's a few weeks in and I stay pretty silent; I just don't know how things will be shared."
3. "Twice a person has joined the meeting to observe, I don't quite know who they are, I feel a little on edge."
4. "I work in another area, so I don't feel qualified to speak on these things."

Answer: Sentence three hints at a physical safety concern because the participant is unsure who the observers are, creating possible uncertainty about personal security, privacy, and physical safety as the intention of the observer is unclear.

2. Trust & Transparency

Nurture trust through open and transparent communication. Ensuring that communication is clear and consistent helps to build trust. Transparency is about also being honest in your communication. As it reduces uncertainty and can additionally nurture trust, while enabling people to make informed decisions.

Top Tips:

- Set expectations: express what you can and cannot do
- Avoid overpromising
- Communicate clearly and consistently, in a timely manner

3. Choice

Offer individuals options and choices, letting them shape the space according to their needs. Approach engagements with flexibility, and be willing to share control of the process, to cultivate collaboration. Throughout an engagement, there may be many opportunities to provide options: from timing and types of support offered, to communication methods and accessibility adjustments. Aim for everyone to have what they need to participate fully and comfortably (see section 4.2).

4. Collaboration

'People need to be involved in decisions that affect them'[xviii].

Share power in the decision-making process and incorporate the perspectives of others, to improve services, policy design and development. Getting people with lived experience actively involved in shaping services, procedures and policies improves the design and impact of work.

People with lived experience already hold deep knowledge and insights from their interactions with services and policies. They often understand the barriers, gaps, and opportunities in ways that others cannot. Due to this, we believe that Experts by Experiences already hold solutions to the issues practitioners may be trying to address. The focus of engaging Experts by Experience therefore, should be on helping to develop the answer to the problem rather than reiterating what the problem is. Moving from reflection to resolution.

5. Empowerment

Draw on the diverse strengths, skills and knowledge of individuals, harnessing their insights. Engagements should be a space where everybody is empowered to speak, share views, and feel safe to do so. As with collaboration, empowerment also involves challenging power dynamics, shifting to a model where people have a voice in decisions.

Prompts: What decisions or responsibilities am I holding that could be shared?

- How might you address power imbalances between facilitators and participants?
- Does your engagement create space for participants to shape activities or outcomes?

6. Cultural consideration

Trauma-informed practice is underpinned by a commitment to addressing systemic inequalities and ensuring equal access and support for all. This means understanding the societal context, backgrounds and lived experiences of individuals, and creating processes that are responsive to different experiences. We need to challenge the forms of racism, discrimination, sexism and inequalities within an organisation. Practitioners need to reflect upon the ways that these issues might dissuade people from participating. When planning an engagement, it's important to think critically about who is involved and who we might need to get involved.

Reflection: Reflect on where lived experiences are different, and where are they similar; What are the additional barriers people may face, and how can these be addressed?

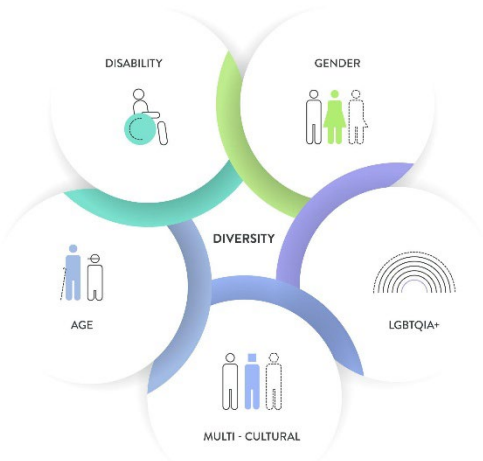
Trauma-informed practice involves an ongoing commitment to reflecting on and improving one's approach. It creates safe, accessible and inclusive spaces for engagement.

2.4. Intersectionality

Intersectionality is a concept developed by Kimberlé Crenshaw[xix]. It describes how different aspects of a person's identity combine and interact to shape their lived experiences.

Individuals are not defined by a single characteristic. Every person holds multiple identities, which may include:

- Gender
- Race / ethnicity
- Sexual orientation
- Disability
- Age
- Socio-economic background
- Faith / cultural identity



As the diagram demonstrates, intersectionality can be visualised as overlapping identities. Each circle represents part of a person's identity, and the overlaps highlight how they may interact influencing how individuals experience systems, services, relationships, bias, and trauma. In engagement settings, these overlaps may influence:

- Perceived safety
- Willingness to share
- Trust in institutions
- Experiences of voice, validation, and power

Experts by Experience do not experience trauma, services, or engagement spaces in isolation. Lived experience is shaped not only by, for example, Domestic Abuse and/or Sexual Violence (DASV), but also by how other aspects of identity influence that experience.

For example:

- A survivor may experience barriers linked to gender
- A racially minoritised survivor may experience both racial and gender-based bias
- An LGBTQ+ survivor may encounter additional stigma, invisibility, or safety concerns

These experiences are not separate or additive. They interact to create **distinct lived realities**.

Rather than viewing experiences through one lens (for example, gender alone), intersectionality provides a framework for understanding the **combined and interacting effects** of social and structural factors.

In the context of trauma-informed engagement, intersectionality is particularly important because:

- Trauma is influenced by social context
- Discrimination and structural inequality can contribute to trauma
- Identity can shape how safe, seen, and understood an Expert by Experience feels

Two Experts by Experience with similar experiences of domestic abuse and/or sexual violence may have very different needs, triggers, and engagement preferences. Without an intersectional lens, engagement risks:

- Oversimplifying lived experience
- Reinforcing feelings of invisibility or misunderstanding
- Missing barriers to participation
- Creating spaces that feel unintentionally unsafe

Why This Matters?

Intersectionality is not about categorising individuals. It is about recognising complexity and avoiding assumptions. Meaningful engagement requires practitioners to understand that:

- Experts by Experience bring whole identities into engagement spaces
- Power, privilege, and marginalisation may shape participation affecting group dynamics
- Psychological safety is experienced differently across individuals
- Stronger trust and relationship-building, particularly due to institutional trauma[xx], may be required.

Reflective Prompts:

Facilitators and organisers may find the following questions helpful when planning an engagement:

- What identities or contexts may be relevant here?
- Am I unintentionally making assumptions?
- How might power dynamics be operating?
- Who may feel less able to contribute with this format of engagement, and why?

3. PLANNING AN ENGAGEMENT

Working with Experts by Experience means working with real people, real stories, and real emotions. It requires more than inviting people into a room. Good planning is about creating the right conditions for safety, trust, and meaningful contribution, before anyone steps into the space.

Before inviting Experts by Experience into a space, practitioners should be clear about why the engagement is happening and what it is aiming to achieve. Building on Welsh Women's Aid's Survivor Engagement Toolkit[xxi], we have developed the following questions to consider when setting up an engagement:

What is the purpose?

- Do you have a clear outcome in mind?
- How do you want people to feel when they leave the room?
- Is the design of the engagement purely to serve the practitioners agenda? How could it genuinely create a space for insight and learning?

What engagement mechanisms are you planning to us?

- What environment do you want to create?
- Is there time for Experts by Experience to fully share their insights and opinions?
- Can you follow-up with Experts by Experience afterwards to check how it felt for them?

Who is going to deliver the role?

- Are you going to have a dedicated member to help coordinate the Expert by Experience involvement?
- Who is going to be facilitating the workshops? For example, is the focus VAWG, where a female-only facilitation group could be necessary
- Do the facilitators have the skills to work with Experts by Experience in an empowering and trauma-informed way?
- Do you have additional support structures in place, such as mental health professionals, safeguarding leads, trusted people that an Expert by Experience can speak to if needed?

"Remember - true engagement is an ongoing commitment, and continuous learning and adaptation are essential to create lasting change"[xxii]

Further reading: Safe and Equal, from Australia, have developed a comprehensive organisational readiness checklist with guidance for those considering engaging people with lived experience.

3.1. Recruiting Experts by Experience:

People have different comfort levels around how their experiences and identities are shared. When recruiting, practitioners should communicate to potential Experts by Experience their engagement expectations, including the types of experience sought and the levels of anonymity available (see Appendix B.1). Here, it is helpful to be transparent about[xxiii]:

- Who can sign-up or apply
- What participation involves
- What work they will be involved in
- How their information will be used and who will have access to it.

Confidentiality is often a significant concern for people with lived experiences and can act as a barrier to engagement. Uncertainty about how personal information will be recorded, shared, or used may create fear or anxiety and lead to disengagement.

Overall, this clarity is important because many Experts by Experience might have experienced forms of abuse and/or exploitation where power and control have been at play. Setting clear expectations supports Experts by Experience – a key aspect of what is lost when trauma is experienced.

Practitioners should make it clear during recruitment that participation is always opt-in, and that people can opt out at any point, for any reason. Someone may initially feel comfortable agreeing but later realise that engaging with their lived experience is more challenging than expected.

Note on recruiting staff members:

Safe and Equal (2020) and Ward(2022)[xxiv] note that staff who identify as having lived experience may find disclosure difficult. Concerns include how sharing personal history might affect their career, relationships with colleagues, or create an "us and them" dynamic within teams. This may affect whether people may sign up to lived experience engagements.

3.1.1. Preparedness to engage

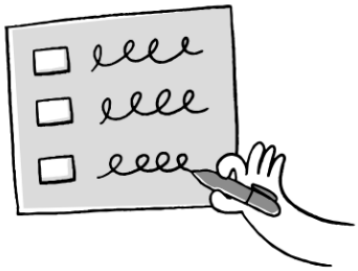
When recruiting, facilitators should explore whether an Expert by Experience is not just willing to take part but also feels ready. For those participating for the first time, the sector highlights the importance of discussing safety, risk, and available support (i.e. through offering clinical supervision). Practitioners should also encourage Experts by Experience to reflect on how engagement might affect them, including their boundaries, capacity, and support needs. Imaakan and Women's Aid (2024) emphasise that Experts by Experience may be at different stages of recovery, and engagement could sometimes interfere with healing.

Consider providing Experts by Experience with materials from this toolkit or other resources found in Appendix B to support them to explore anonymity options (Appendix B.1) and assess their readiness to engage (Appendix B.2.1).

3.1.2. Renumeration

It is important to recognise the time, labour, and emotional energy involved so Experts by Experience feel genuinely valued for their expertise. Across the sector[xxv] it is recognised that payment for participation should be carefully deliberated by the organisation depending on who they are and the engagements requirements. In these circumstances practitioners should explore having a variety of options to receiving recompensation.

Facilitators should ask:



- **What can you offer back in exchange for people's time, knowledge, and emotional labour?**

This might include:

- Personal and professional development, such as training courses or formal learning opportunities.
- Certificates that support ongoing development and future participation as lived-experience voices.
- Recognition of the difference involvement has made.
- Payment or gift vouchers.

Further budget considerations should also include travel expense, support with covering childcare or offering childcare, and accessibility costs where required. For more information on this see NHS England's policy on working in partnership with people and communities.[xxvi]

3.2. Integrating support into the engagement plan

As previously mentioned, talking about past experiences can lead to re-traumatisation and/or listening to other experiences can lead to vicarious trauma. Even with the many trauma-informed considerations outlined in this toolkit, it is not possible to fully control the reactions of individuals during engagements. Therefore, it is always necessary to make sure that safety measures are in place to support Experts by Experience throughout the engagements.

3.2.1. Providing organisational support:

Providing optional debrief and check-ins are a critical part of trauma-informed practice. It ensures that any impact generated from the session can be acknowledged and supported. Ensure to communicate that a designated practitioner will be available for a debrief following sessions.

The support you can offer in these situations is emotional support, not counselling, unless you are specifically trained and employed to provide it.

Emotional support is about listening, believing, and validating individuals' emotions. Where the impact requires a more guided intervention, or where Experts by Experience might not want to speak to a staff member they know, ensure they are aware of other available services such as Employee Assist Programmes[xxvii], clinical supervision, or other support services. This ensures that individuals have a safety net in place.

Signposting individuals to other support services should be relevant to the issues they are facing. An existing directory should be at hand to facilitate that transition. Organisations could be:

- Helplines (use 'Find a Helpline' to find relevant services)
- GP's and/or NHS Talking therapies
- Statutory services such as police, social services, or social housing.

Finally, 1:1 supervision with your Experts by Experience staff, if relevant, are not only moments to discuss work and any updates but to also have an emotional check-in.

Note for facilitators: Acknowledge that the difficult conversations and stories you hear can also impact you. Make yourself aware of the support structures available to you and practice self-care before and after sessions.

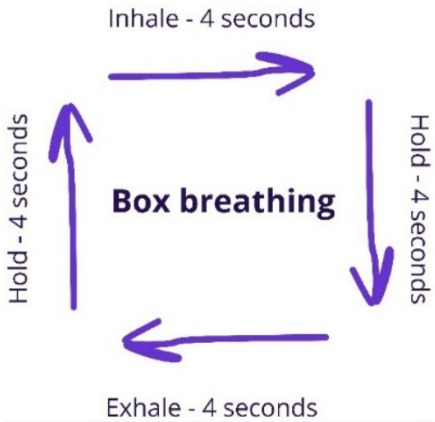
3.2.2. Encouraging self-care

Self-care activities and habits should be tailored to a person's needs and preferences. It is an ongoing practice to support people in maintaining their capacity to continuously engage in sessions. While this form of care is rooted in the self, there is a shared responsibility on the practitioner's part to ensure this is consistently practiced by Experts by Experience. For example:

- When recruiting, discuss their support networks and any existing self-care
- During check-ins - well-being, e.g. through 1:1 supervisions, remind of their support structures and practices when necessary
- If engaging people during work hours, e.g. if staff members are coming to share their experience, ensure they have time off after engagements to decompress and check-in with themselves.

Self-care looks different to everyone. Here are some examples of how we practice self-care:

- Crafting to reconnect with my body
- Breathing exercises[xxviii], for example, box breathing
- walking, reading, meditation, connecting with family, friends, cooking, watching a favourite movie, listening to music
- Eating healthy food and using daily aromatherapy, relaxing bath



Appendix C has a set of cards that practitioners can print and offer Experts by Experience to support their self-care.

4. DURING ENGAGEMENT

Engagements can be safe and insightful spaces if trauma-awareness, core principles and attentive planning are then put into practice during sessions. Here, practitioners should pay close attention to their facilitation techniques, how they build a safe and comfortable session, and the after-care support that is offered.

Remember: People are not there to relive painful experiences — they are there to share insight, perspective, and learning. To look forward and use past experiences for future positives.

4.1. Trauma-informed facilitation

Facilitating spaces that involve lived experience requires more than good questioning or timekeeping. It asks facilitators to be emotionally aware, ethically grounded, and responsive — both to participants and to themselves.

Apply the Six Principles of Trauma-Informed Practice, as explained earlier (2.2.1):

Safety, Trust and Transparency, Choice, Collaboration, Empowerment, and Cultural Consideration

Listening and appropriate language

Facilitators play a key role in shaping whose insights are heard and how they are treated. Being heard is more than being given a moment to speak.

Active listening is a core skill of facilitation[xxix], and central to trauma-informed practice. It involves paying attention to both verbal and non-verbal cues, hearing what someone is expressing, and checking ones understanding by breaking participant's points into smaller parts and reflecting them back. It also includes noticing who is dominating the conversation and who may need more space or encouragement to contribute.

Part of active listening is also mirroring language used. Appropriate language can mean respecting how people self-identify and the terms they choose to use. For instance, some may use the term victim, others survivor, and some may not wish to use either term. It's important to allow people to share their lived experiences in their own words and reflect that language back to them. This includes being attentive to avoiding jargon, acronyms, and clinical language that can make discussions feel exclusive.

Framing questions with care

A key skill of facilitators is to support participants to identify, explore and develop their understanding of the focus area[xxx]. Questions become a facilitators best tool to prompt thought and idea generation. However, the way questions are framed can either invite insight or unintentionally open a therapeutic space.

For example:

- Asking *"Can you tell me what happened to you?"* is likely to lead to detailed disclosures.
- Asking *"If the way things were done changed, or if support were offered differently, what would that look like?"* centres learning and forward thinking.

Focus on experiences as sources of insight, not stories to be delved into. As with any good facilitation practice, engagements shouldn't be spaces of extraction, they must also focus on hope and informing change.

Offering emotional support

It is important to understand the boundaries of your role as a facilitator. Facilitators are not therapists or counsellors, even when emotional topics arise. Their role is not to treat trauma, but to remain responsive to its impact, keeping participants' wellbeing at the forefront.

It is important to recognise when someone is being affected by the discussions. This may show up through withdrawal, anger, or changes in tone, participation, or behaviour. At times, however, these signs are subtle. In these circumstances, planning engagements with clear feedback channels helps ensure people feel able to express when something is difficult or overwhelming.

Acknowledging the impact on yourself

Facilitators are not neutral observers and it's important to recognise that many time's practitioners come to these roles with their own experiences. Holding space for lived experience can have an impact, emotionally, mentally, and physically, on oneself.

Facilitators are encouraged to reflect on:

- Are you aware of the risks of vicarious trauma or emotional fatigue? (see section 2.1)
- Have you factored in time to reflect on the engagement and recognise the impact facilitation may have on you?
- Do you have plans to debrief afterwards with a colleague or trusted peer?
- Have you developed your own self-care practice? (see section 3.3.2)

Looking after yourself as a facilitator is part of trauma-informed practice.

4.1.1. Navigating challenges during engagements

Even well-planned engagements can present challenges; groups can be unpredictable. Trauma-informed facilitation is not about preventing difficulty — it is about responding to it with care. As noted by Welsh Women's Aid (2022) "Remember to challenge the behaviour rather than the person"[xxxi] where your role is to keep the safe space for all, not the few, which requires challenging behaviours in the space.

Below are common challenges we've identified that may arise during engagements, along with suggested responses. Thinking through these in advance helps facilitators feel prepared and confident in their approach. Overall, following best practices in facilitation and careful framing of questions can help mitigate some of these harms.

Challenge	Response
Conflict or aggression (often linked to anger)	Requires calm, confident facilitation to identify and challenge the behaviour. Learning to defuse situations is a specialist skill and should not be underestimated.
Emotional upset that disrupts the flow of the session	Acknowledge the emotion rather than shutting it down. Allow space for feelings to be expressed. Avoid ignoring or minimising what is happening. If you notice someone getting particularly distressed during a session, it is good practice to reach out to them to check-in, offer additional support, and signpost to relevant services.
If a group begins moving deeply into trauma	Gently shift the conversation by asking a different question. Steer the discussion towards something grounding or forward-looking. Avoid allowing the session to become focused solely on trauma
One person repeatedly sharing the same story and limiting others' input	Gently redirect the conversation back to the group or the agenda. Refer to group agreements defined for the engagement (see section 4.2)
Silence or nervousness about speaking	Start with light questions or icebreakers to help people ease into participation
Advice-giving between participants	Offer a gentle reminder that advice-giving is not the purpose of the space

4.1.2. Responding to a disclosure

Practitioners should ensure they take the time to refresh themselves with their organisations policies and procedures related to Safeguarding before any engagement takes place.

At the beginning of each session, facilitators will need to share information about confidentiality and when this will be broken due to safeguarding concerns; and that if this is raised concerns will be discussed with them first. For instance, when a facilitator becomes concerned about the safety of a child or a vulnerable adult. There is a duty to act.

If a disclosure does occur, practitioners shouldn't panic. Practice active listening, believe them, and create a safe space to explore their situation. Most of the time there is a senior manager at the organisation who will discuss the case and decide on next steps and whether to make a referral to social services.

A final reflection: Facilitating this kind of work requires compassion, attentiveness, humility, and care. It asks the facilitators to hold boundaries while remaining human, responsive, and present.

4.2. Practice tips on building a session

While each engagement may require different approaches, the following information provides some tips on things to consider; many of which are a combination of what we'd like to see happen more in engagements and our experiences of meaningful spaces. When read all together these practice tips communicate the mindset needed for this space.

Clear communication of expectations

Facilitators should consider contacting Experts by Experience in advance to introduce themselves, explain the session structure and confirm who will be present. It is suggested to provide the agenda in advance so that people know what to expect and prepare emotionally.

When contacting Experts by Experience, invite them to ask questions and/or share concerns. This enables a space to express any needs and begins building rapport, which can increase comfort and trust during the session.

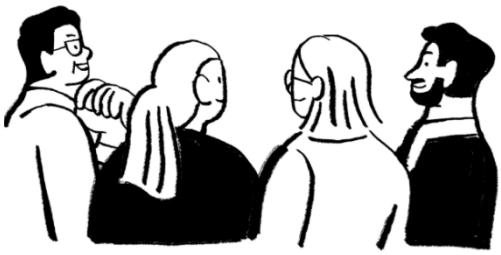
Before the session begins, facilitators should revisit confidentiality — explaining what will be written up, how information will be handled, and that discussions are kept within the group and not shared outside the room.

It is suggested that practitioners develop and share a **group agreements form**[xxxii]. This is an agreed-upon set of ground-rules and processes that have been created to support Experts by Experience working as a group effectively, respectively and in a trauma-informed way. This supports with providing predictability and shared expectations to reduce anxiety and conflict. See Appendix D for an example.

Who is in the room?

Experts by Experience are experts of their own lives and seeing them beyond just their experiences is key[xxxiii] – they are professionals, parents, creatives, and much more. Lived experiences are never uniform, and identity may influence perspectives and priorities; no individual may speak for an entire group. Therefore, practitioners should pay particular attention to the diversity of experiences they invite/recruit to participate in the interventions.

It is recommended to have two facilitators[xxxiv], where all or at least one is trauma-informed and able to provide emotional support if a person becomes upset or leaves the room. Besides the facilitators, practitioners should carefully consider who else from the organisation is attending and why. For example, having eight policymakers observing the workshop in a room with five Experts by Experience can make people feel outnumbered and observed. Consider if previous institutional experience with the professionals invited into the room may affect participants trust. If additional professionals will be attending, ensure that Experts by Experience are made aware who they are and why they are there.



Location

Locations matter when planning engagements because the space should feel safe, comfortable, and supportive. It should be somewhere people can come together and share their stories openly.

A suitable venue is one that is accessible for all – with a lift, for anyone who is a wheelchair user or has limited mobility and reachable via public transport and/or have optional parking. Sometimes online formats can be most accessible for individuals. This can be important to consider as physical and/or psychological factors can be barriers for in-person sessions.

People might have not only experienced trauma in the personal or interpersonal aspects of their lives but also by the very institutions that were meant to protect them[xxxv], like hospitals, police, courts and so on. Paying attention to where the engagements are held in person can help mitigate compounding barriers.

If in-person, consider room layout

A safe space is one where people feel comfortable, relaxed, and able to share openly so they can fully engage in the process. The physical environment plays a significant role in this. Avoid clinical or overly sterile settings that may resemble hospital environments and feel unsettling for some participants. Consider the decor, could any artworks or object be potentially triggering or unsafe?

If possible, choose a room:

- Where the temperature and lighting can be adjusted depending on needs and preferences
- That is quiet and private where people cannot be observed from outside with a “Do Not Disturb” sign.

Arrange chairs in a circle rather than a classroom-style layout to reduce hierarchy. Ensure there is enough room for participants to more around - stand, stretch, or step out if needed. Due to previous experiences of trauma, some individuals may prefer to sit near a door to leave easily or a window to not feel trapped in the room, explore if the layout could allow for this choice.

Consider including the following items as practical signals of care in the room:

Water, refreshments and snacks

Tissues – places to the side rather than in the centre – to signal that they are available if needed, without implying that emotional distress is expected

Notebooks or paper so the participants can doodle or write as they need to/ pens for journaling

Fidget gadgets/ toys can be a good distraction/ focus for people

Colouring books/pencils/ paper/paints

Essential oils

Finally, consider allowing participants to arrive early where participants can settle in, meet one another informally, and decompress and relax before beginning.

If online

For online formats, it might be helpful to discuss camera policies with the group. For some people they might feel more with an all cameras-on policy whereas for other individuals' cameras off could add another layer of anonymity. Consider if people will have access to online platforms and know how to use it. Finally, explore allocating a facilitator who can monitor the screen and chat so that participants have multiple ways to take part and feel equally included in the online session[xxxvi].

Regular breaks and time-outs

Participants should be made aware that they can leave and re-entre the engagement as needed for space and support. Ensure that the structure of the engagements includes taking regular breaks to give people moments to recharge, regulate and check-in with their emotions.

Closing the session

Closing is an important part of engaging with Experts by Experience. It allows for an emotional check in, assesses distress and helps prevent the person feeling overwhelmed or dysregulated. It is an opportunity to pause and acknowledge participants' inputs and recognise personal growth by sharing their stories of resilience and hope. Validation supports with reducing shame and self-blame, which are common in domestic abuse and/or sexual violence. Therefore, offering reassurance that their feelings are valid can lower feelings of isolation and abandonment.

A brief recap of what was discussed in the session and next steps provides structure and prevents confusion. This recap should also be an opportunity to remind individuals of available support and self-care and offer signposting to relevant services. This gives individuals options to seek further assistance after the session.

Using grounding exercises at the end of sessions can help regulate and calm the nervous system before the session ends.

Benefits of Grounding Exercises[xxxvii]:

- Helps connect to the present moment.
- Reduces anxiety and panic by shifting focus away from racing thoughts.
- Improves emotional regulation.
- Builds a sense of safety and control.

- Calms the nervous system, reducing fight/flight responses.
- Lowers heart rate and muscle tension.
- Improves breathing pattern, encourages slow deeper breaths.
- Improves concentration and focus.
- Interrupts negative thought.
- Enhances self-awareness.

This is quick and accessible, can be done anywhere, needs no equipment, allows empowering self-help tool to support resilience and independence.

Tip: Appendix E has an example of leading a grounding session to help guide practitioners. Appendix B.2.2. has a list of questions you can offer Experts by Experience to explore the impact of engagements on themselves.

A final note:
We understand that all these factors may not be possible depending on where you work, what materials are available, and the budget. However, what we hope to communicate is that what is visible in the room can signal the kind of space people are entering — calm, considered, and supportive.

5. POST-ENGAGEMENT: FOLLOW-UPS AND FEEDBACK

After the engagement itself, the work with Experts by Experience isn't finished. A meaningful process can include sharing back what was gathered, creating space for wrap-up conversations, and offering practical ways for people to stay involved if they choose to. This stage is about ending with transparency and care.

Meaningful engagement does not end when the workshop or consultation finishes. Closing the loop/sessions is critical in trauma-informed practices.

5.1. Reviewing contributions

Exerts by Experience should also have opportunities to review, refine, or add to their ideas after the session, whether through a designated contact person, a shared chat space, or tools that allow later additions. This supports people to remain in control of their contributions.

Facilitators should recognise that:

- Quotes or examples can sometimes include identifiable features, even when anonymised.

It is important to check with people how they feel about their words being shared more widely.

Where possible, Experts by Experience should also be able to review the final drafts of any materials, to ensure everything discussed was captured. Furthermore, this ensures that they are still comfortable with having their stories published, that their quotes are not taken out of context and to confirm that the language used reflects their own voice rather that it being reshaped into the organisation's tone.

It's also important to clearly communicate what will happen to their data going forward—how long it will be stored, whether they can request the removal of their stories at a later stage, and if their contributions might be repurposed or used in other projects or contexts.

5.2. Providing feedback following an engagement

Individuals often become Expert by Experience because there is a desire to make a difference. It is, therefore, important to show what happened to their contributions, how their insights shaped the work, and where the project is heading. Essentially, how their input has driven change.

What if I have nothing to feedback?

It is understandable that systemic change can take time, but feeding back impact does not need to wait for large-scale transformation. Meaningful feedback can include smaller, individual, or procedural changes that have already taken place. For instance, you can share how their input has:

- Influenced your way of thinking
- Shaped a decision
- Adjusted processes
- Changed wording in a document
- Adapted staff training
- Or contributions have been shown to senior decision-makers.

It's about showing that the contributions have led to tangible difference.

The type of mechanism you use to feed back to Experts by Experience will depend on the context of your engagements, the timescale, and scope of the work. This might include written summaries, visual timelines, short update emails, or a final report. Where possible, we always recommend a closing or wrap-up session as this provides a space for Experts by Experience to also share back, challenge or contest any changes made, and ensure their voice is still represented accurately.

Whatever method you choose, the aim is to make sure Experts by Experience can clearly see how their contributions have shaped the project, what decisions were made, and how the work will move forward.

5.3. Offering a wrap-up session

A wrap up session, aims to bring people together to mark the end of the work and acknowledge the labour and celebrate the contributions of Experts by Experience. It also supports emotional closure, helps prevent people leaving with unanswered questions, and reinforces transparency, authenticity and shared ownership of the work.

This could be captured through:

- An event bringing Experts by Experience, coordination, managing staff, and policymakers together to share outcomes and memories of the exchanges
- A poster or plaque summarising what was developed and acknowledging who participated (while being sensitive to disclosing participants names and using pseudonyms where agreed)
- A newsletter where individual reflections of people's experiences are collected and shared, serving as an opportunity to reflect and remind each other of their achievements
- A group activity where they co-create a piece of work that captures their experiences
- A celebratory gathering, acknowledging the kinship that might have developed across the group and allocate funds for a shared experience like a meal or an activity.

Avoid giving organisational merchandise, for example, mugs or pens with branding that are devoid of sentiment.

6. FINAL REFLECTIONS

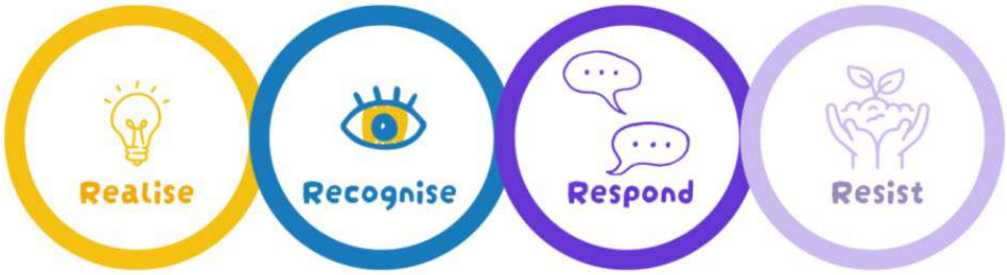
Engaging Experts by Experience is a vital part of ensuring that decisions are shaped by the needs and perspectives of the people most affected. When done well, this makes services more relevant, accessible, and culturally sensitive. Sharing lived experience is powerful and can be healing for those who choose to participate.

Taking a trauma-informed approach, and some of the suggestions offered in this toolkit, is essential not only because the risk of harm is higher in these contexts, but because without it, practitioners cannot create the conditions that allow Experts by Experience voices to be fully heard.

APPENDICES

A. Engagement

The Four Rs[xxxviii]: This provides the foundation for understanding how we hope to engage with individuals who have experienced trauma.



Realise

Realise the deep and widespread impact of trauma and possible pathways to recovery.

Recognise

Recognise the signs and symptoms of trauma, not only in the people you engage with, but also amongst their families, friends, fellow staff and those involved with systems and organisations.

Respond

Respond by fully integrating trauma-informed knowledge into all policies, procedures, and practices.

Resist

Resist re-traumatisation. Actively shape practices, language and environments to prevent harm, and re-traumatisation.

Engagements can be grouped into three types of interactions, which involve: **doing to, doing for,** or **doing with**.

Doing to treats participants as recipients of decisions. For instance, participants are sent guidance about a new set of rules and training on it They were not involved in the development of said rules and are simply being educated on what these rules are at the end of a process they were not part of.

Doing for involves people being asked to input their views but they have limited control over decisions that are made. Consultations might happen throughout the decision-making process and people can

provide their feedback on actions taken. The drawback of this approach is that it can be too late in a delivery phase to truly shape a piece of work, leading to avoidable oversights and problems later down the line. People often find these can feel extractive or like a 'tick-box exercise' rather than their voices having a more meaningful impact.

Doing with means engaging participants as **active partners** throughout the process. They help shape approaches, design outputs and influence outcomes rather than solely give feedback. Peoples lived experience directly informs the work and improve the impact.

Overall, when working with Experts by Experience, the 'doing with' approach aligns more closely with trauma-informed principles. Unlike the 'doing to' where Experts by Experience would be passive recipients of decisions, or 'doing for' where their influences are limited, 'doing with' redistributes power and embeds collaboration throughout the entire process.

What are the ways we can co-produce and co-design with Experts by Experience?

Prototype ideas together: create and test possible solutions together.	**Map participant journeys using a tool or service to see where changes are needed.**	**Involve participants early in the process.**
Collaborate in defining and understanding the problem.	**Use feedback channels to continuously gather input and make improvements after implementation.**	**Decide the outcomes together!**
Monitor and evaluate services, with participants as peer-evaluators.	**Make joint decisions. (Use group decision-making approaches to problem solve and find consensus, such as dot voting.)[2]**	**Share data and insights transparently: involve participants/collaborators in interpreting and making suggestions.**

Further Reading

- **The Family Violence Experts by Experience Framework Report**
- Working in Partnership with People and Communities NHS England
- The report offers further illustrations of how trauma-informed practice links to the ladder of engagement (see pages 16 and 25). https://bristolsafeguarding.org/media/dlhebkrr/family_violence_experts_by_experience_framework_report.pdf
- **Co-design in Policy: Learning by 'Doing'**
- Practical insights on how you can involve people in policy design, from the UK governments Policy Lab.
- https://openpolicy.blog.gov.uk/2019/01/11/co-design-in-policy-learning-by-doing/
- **Innovation for Culture Whitepaper**
- Explores creative approaches to collaboration and co-production in organisations.
- https://www.boptheatre.co.uk/wp-content/uploads/2021/09/Innovation-for-Culture-Whitepaper-English.pdf

B. Supporting materials for Experts by Experience

B.1. Levels of Anonymity

We recognise that participating in engagements can be a complicated experience, particularly when navigating what you do and do not want to share. Everyone has different boundaries and levels of comfort when engaging on topics related to their own lived experience. It is important to underline that participation does not require sharing your personal experiences. You may choose to participate by sharing ideas, feedback, priorities or recommendations, without discussing any details about your life. If you do decide to draw on personal experience, that is entirely your choice.

The 'Ladder of Anonymity' has been created to help you choose how your contributions may be shared or attributed. It is intended to support autonomy, safety and informed choice throughout the engagement process.

It is important to note that you are not required to share more than you wish. You may feel comfortable with one level of sharing, and later in the process change your mind. You are in control of what you share and how.

Anonymous

Your identity is not known, even by the facilitator. No names or contact details are recorded and your words are not directly quoted.

How it might look like:

- Provide anonymous written submissions via:
  - **Digital form** including online forms with no email collection (possible via common platforms such as Microsoft Forms or Google Forms), or anonymous feedback platforms, or
  - **Physical forms** submitted via a secure drop box in private locations or indirectly collected.
- Feedback is collated by an external organisation, that strips all information which can be used to identify individuals:
  - No names or other identifiers.
  - No addresses, emails, or phone numbers.
  - No direct quotes are used.
- Quotes are paraphrased to prevent traceability.

💬 "I want to share my views, but I do not want my name, voice, or anything about me to be recorded."

Confidential Circle

You may attend in-person or online engagements, and so your identity is known within a small group. Your contributions can be shared externally (with your consent) but names and identifiers are not attached.

What it might look like:

- Clear group agreements to ensure confidentiality of information shared.
- No recordings.
- No public sharing of individuals names or any identifiers.
- The opportunity to review and approve any quotation before publication.

💬 "You can share what was said, but not who shared it."

Pseudonymous or Partial Attribution

Your contributions may be shared publicly (with your consent), alongside some identifiers such as, your age or gender, but not your name. You may be referred to with a pseudonym, initials, or general descriptor.

As with all attributions you should be able to approve the exact wording, how you are described, and the context in which your words appear.

How it might work:

Before any information is shared outside of the group or externally, outside of the organisation ensure that:

- Names and direct identifiers are removed.
- Images and videos may be recorded and shared, but identifiers are removed with blurring, only showing your silhouette, voice distortion or overdubbing (original audio is replaced with another's voice).
- Locations, departments, dates, and contextual details are generalised.
- You may choose a pseudonym or descriptor (for instance, "Participant, Manchester").
- You are offered the opportunity to review and approve any quotation before publication.

💬 "I am comfortable being quoted and sharing a bit about me, but I do not want my real name to be shared publicly."

Sharing with a limited audience

Your name or image is shared only with a defined, restricted audience. Feedback and quotes are attributed to you in this limited group, and no further sharing occurs without your consent.

The survivor chooses to be identified in a specific, contained setting. You can choose at any time to withdraw from this space.

What it might look like in practice:

- Participating in a private meeting with specific, relevant stakeholders and teams. Attendance is restricted and you are informed of attendees in advance.
- Named contributions in an internal document for specific teams or staff members.
- The scope of the intended audience is made clear and there is clarity on future usage.
- You have the chance to review and approve any attributed materials.

💬 "You may use my name and images of me but only for this departmental report."

Public Attribution

Your name and/or image may be used publicly. Your words and likeness may be included in publicly accessible reports, media or events. Here you will have agreed to being identified publicly but you retain the right to withdraw.

It is worth noting that once something is released publicly, it may be accessible by anyone. While the organisation should make reasonable efforts to remove content, for instance by erasing content from official channels, it may not be possible to completely retract all copies.

What it might look like:

- **Written contributions with attribution:** quotes are included in publicly available reports, policy documents or online articles with your name.
- **Images or videos are shared:**
  - Photographs, illustrations, or videos of you included in public-facing materials.
  - Social media posts or content on websites showing your image or name.
- **Public engagements** where you may not be made aware of all the attendees.
- Speaking directly or having another share your contributions in open forums, such as organisation-wide meetings, conferences, workshops, panels, or public events.
- Participating in Q&A sessions, moderated discussions, or advocacy panels.

- **Recorded media:**
  - Videos where you are visible or your voice is heard are uploaded online (this could be to platforms such as YouTube, organisation websites, or social media channels).
  - Audio recordings or podcasts where your contribution is attributed.
- **Campaigns & advocacy:**
  - Contributions are shared in public awareness campaigns, advocacy videos or community events.

💬 "I am comfortable with my name and photo being shared alongside comments, for anyone to access."

Important Note:

Participants must first provide consent for the use of their name, image, or voice, with a clear explanation of where the content will be shared, what will be shared and who will have access to it. Potential risks will need to be assessed by the organisation, and you can still withdraw consent at any time (even if the removal of all materials may not always be possible).

Data handling safeguards

When handing participants information ensure that:

- Identifying information is stored separately and securely.
- Access is restricted to named staff only. (Ask yourself, who needs to know which participants are involved? Do they require this information to carry out their work?)
- There is a clear retention and deletion timeline.
- No information is shared beyond the agreed scope.

B.2. Questions for Experts by Experience to ask themselves

B.2.1. Questions for before engagement

This list of questions for Experts by Experience has been developed to help you explore whether you feel ready to participate in an engagement:

- Do I feel physically and emotionally ready to take part in this engagement?
- Do I have time to prepare for the engagement?
- Will I personally benefit from this engagement?
- Do I feel like participating in this engagement could make a difference?
- Do I feel like the engagement will be a safe space for me? If not, what could help make it one? Can I pass this information onto the team?
- What are my boundaries during the engagement? How much do I feel ready to share?
- What are my coping strategies and support structure do I have before and after the engagements?
- Do I know what support the organisers will offer me when I need it?

Other useful resources:

- Breaking the Silence
- self-audit-checklist.pdf

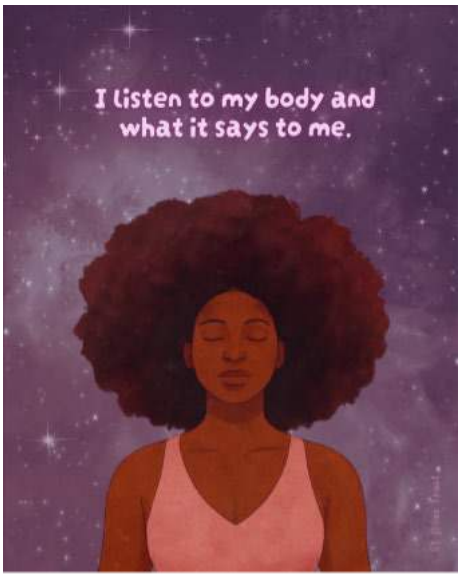
B.2.2. Questions for checking-in post engagement

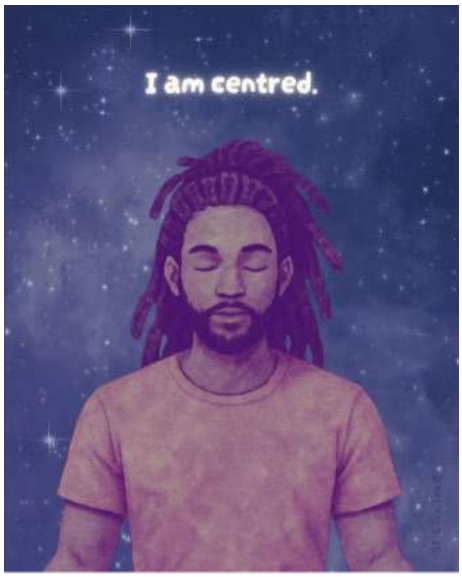
This list of questions is for Experts by Experience. It has been developed to help you explore whether you feel ready to participate in an engagement. It is understandable that when you share a space with other people's stories of trauma, it may lead us to question our own experiences and recovery process. Please remember everyone's journey and experience is unique, you are where you are and that is ok.

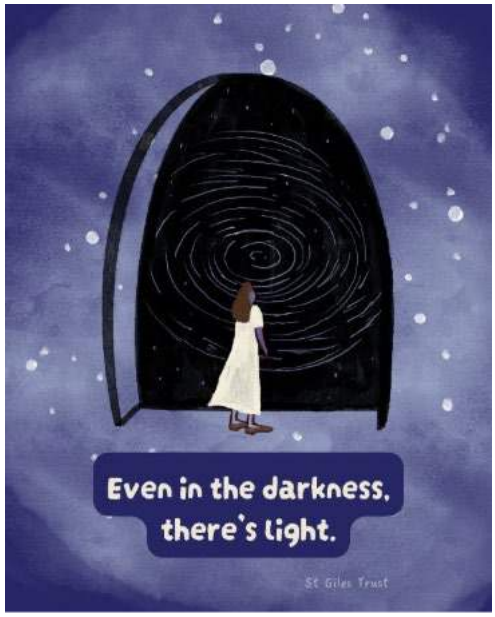
- How did I experience the engagement?
- What feelings have come up for me after listening to other people's experiences?
- Do I feel like I might have been comparing my experiences to others?
- If yes, can I identify what protective factors (e.g., support, money, family) could have helped with their recovery?

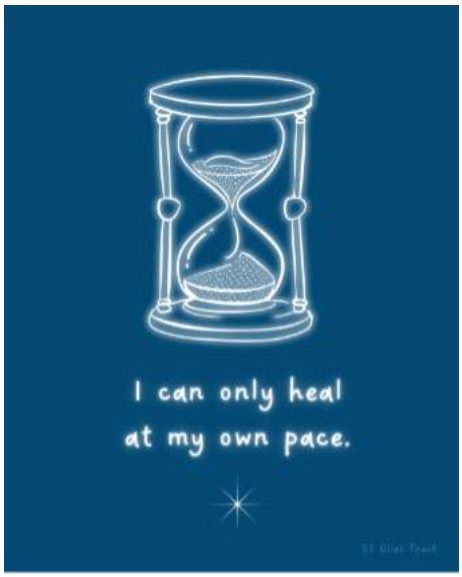
- How might have participating in this engagement have helped you to understand yourself and your experiences better?
- Do I feel like I need to follow up with the organisers about anything that has come up for me or provide feedback?
- Have I had a moment to check-in with myself and practice self-care?

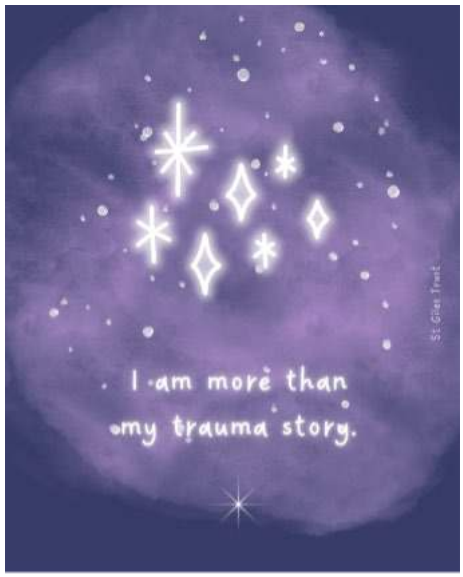
C. Self-care support cards

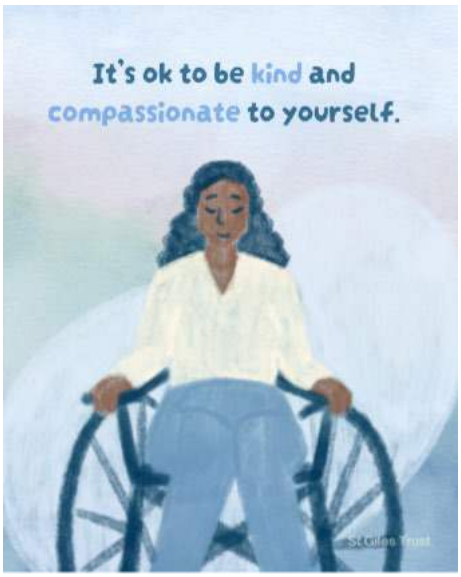


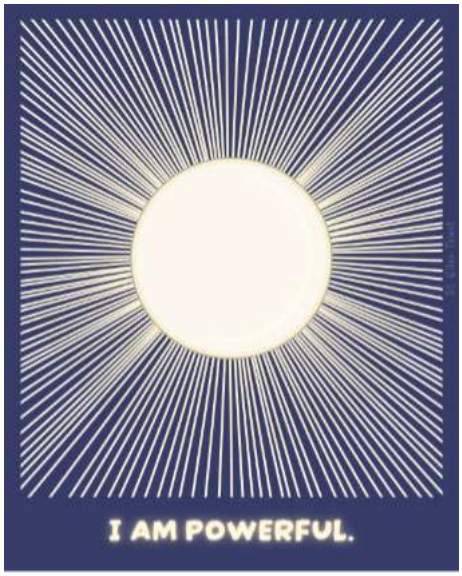


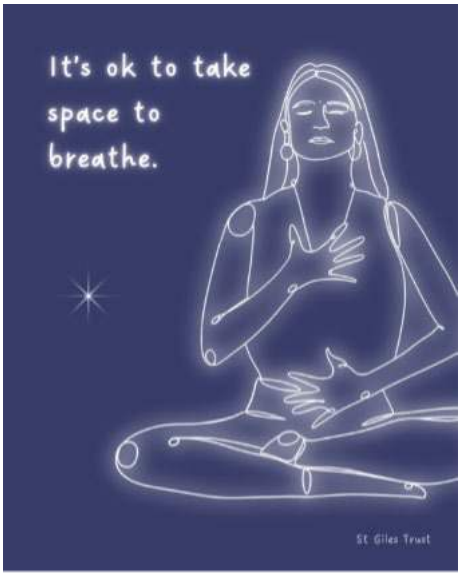


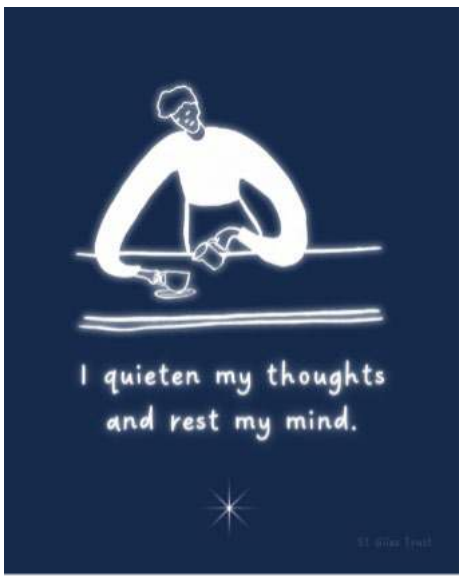












D. Group Agreement form example

Group Agreement - "helping us work together."

The group agreement is a set of ground rules and processes that have been created to support us working as a group effectively, respectively and in a trauma-informed way. By joining us you agree to follow this agreement. If you have any questions or would like to change/add/delete anything, please contact the organiser. We are always interested in understanding how we can improve.

Confidentiality

Only share what you personally feel comfortable sharing. If personal/sensitive information is disclosed that deviates from the purpose, you will be redirected to a more appropriate support group.

Do not share personal information outside of the group.

Communication

- Listen carefully to what others have to say and actively work to understand the perspective and experiences of others in the group.
- Allow everyone to have their say.
- Humour – be mindful that this is not offensive to others.
- Try not to monopolise the discussion.
- Everyone should be able to express how they feel without judgement.
- Respect other viewpoints and avoid the use of dismissive or negative language.
- Be mindful of the words you choose. Avoid making personal attacks or using disrespectful language.

Respect

- Challenge the view, not the person.
- Respect individual personal boundaries.
- Promote a relaxed feeling in the group.

Conduct

- Timekeeping – be punctual when joining online meetings.
- Allow people to leave the group.
- Challenge discriminatory or oppressive behaviour.
- Produce a way to challenge disruptive behaviour.
- Aim to resolve disagreements within the group.

E. An example of leading a grounding session:

We're coming to the end of our session now.

Explanation: Gently signal the ending, this helps everyone shift from sharing mode back into everyday life

I would like to offer a short Grounding moment to begin to bring the session to a close, you're welcome to join in, or just take this time in your own way.

Ex: offer grounding as self-support, not facilitation, avoid anything that feels therapeutic or directive, such as, deep breathing, or body scans

Take a moment to notice your feet on the floor, or your body in the chair.

Name quietly to yourself: Two things you can see around you.

Notice one thing you can hear.

Take one slow breath.

Today we have focused on sharing our lived experiences, listening without fixing, and supporting one another in a way that feels safe and respectful. This information is offered to support learning and change. There is nothing to resolve or carry forward, this space stays here.

E: this enables the re-orientation to the present and helps close emotional loops, in a mutually respectful and inclusive way

Give a gentle aftercare reminder for example: after these sessions it might be helpful to do something grounding, such as a walk, hot drink, listen to some music, or connect with someone you trust, use whatever already works for you, offer more support options (local) NHS links

This session is now closed, thank you for holding the space respectfully. Please take a moment before returning to your next task.

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