Involving survivors of trauma and human rights abuses in research – Reflections from a preliminary internal enquiry

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The article describes aspects of a preliminary internal enquiry into the perspectives of survivors of trauma and human rights abuses on research within a non-profit human rights organisation. The outcomes of the study led to the production of an internal report and lay summary of the findings, as well as an information leaflet that introduces the process and purpose of research in the organisation. The aim of this article is to share reflections on the process and the recommendations made by the service users with other clinicians hoping to engage survivors of human right abuses in research.

Keywords: *Service user involvement; Stakeholder engagement; Psychological trauma; Human trafficking; Expert by experience.*

Background

WHILE there is some guidance on priority setting for survivors of violence and abuse in the UK (Robotham et al., 2019), there is overall, a lack of best practice guidance for collaborative research with survivors of war, human trafficking and torture. A working definition of trauma-informed practice from the UK government includes the principles of safety, collaboration, empowerment, choice, trust, and cultural consideration (The Office of Health Improvement and Disparities, 2022), but a detailed, substantive understanding of what a trauma-informed approach to research looks like from a survivor perspec-

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tive is largely missing from the current literature (but see Shankley et al., 2023) for an account of practice-building in the UK).

As a charity that supports survivors of human trafficking and torture and other human rights abuses, we were keen to ensure that our research strategy and research outputs were both important to, and inclusive of, our service users. A small preliminary internal enquiry was therefore conducted to inform the organisation's research strategy, to help select proposed research projects and to better understand experiences of, and barriers to, participation in research projects.

The internal enquiry

We asked 14 service users in either one-to-one or focus group formats about what they knew about research, what they thought of the research the organisation had been involved with, and whether, or how they wanted to be more involved in the research that was carried out (rather than assuming that our goals of co-production and increased participation were goals shared by our service users). Service users that participated in individual interviews were selected as their educational background suggested that they may have had some experience of research in general terms. Service users that participated in the group format had a wide variety of educational experiences and were part of an established group who met regularly with staff members to discuss and offer expert opinions on various aspects of policies, procedures and practice at the organisation. Participants were English-speaking service users with diverse countries of origin at various stages in their applications for leave to remain in the UK .

Aim of the article

The aim of this article is not to present the full findings of the study, but rather to summarise some of the findings and reflect upon the process and the recommendations made by service users for those hoping to engage survivors of human rights abuses with research. We obtained retrospective consent from the service users who participated to publish the material presented here.

Reflections on methodology

Reflections on recruitment and interview construction

A prominent limitation of the study is the selection of English-speaking service users as participants. We readily acknowledge that this selection criterion is exclusive and far from representative of survivors of human rights abuses in the UK. However, given limited resources and the preliminary nature of the study, we chose this as starting point, as it meant that we could consult our service user forum, who are English-speaking, and skilled at working together as a group of consultants.

When designing the interview topic guide, we reviewed our existing and ongoing research projects, as we hoped to gather opinions as to what the foci of research at the organisation should be. Given the trauma-focused nature of some of the research that had been carried out, we shared concerns about provoking distress or triggering re-experiencing symptoms for some survivors. We were aware that many people have very well-founded reasons for not wishing to be exposed to trauma-related material. We decided to share 'neutral' examples of research, such as the effectiveness of a form of psychotherapy on survivors and in doing so, we self-censored. This meant that participants were shielded from hearing about research that directly explored the impact of specific traumatic experiences, and it also meant that participants were deprived of the opportunity to tell us what they thought and felt about research of this nature. Therefore, the opportunity to further enrich the discussions about researching sensitive or potentially sensitive topics was lost. This is a key example of poor practice in service user co-production. With hindsight, it would have been most appropriate to consult the group about the level of detail about trauma-related research first, and not to make assumptions about their 'robustness' to hear about challenging topics.

This matter, and the decision to approach English-speaking people in the first instance, clearly highlights the need for co-production with experts by experience (EBEs) in all aspects of research and we recognise the potential bias of a solely researcher-led process on the findings of this study.

Reflections on practical barriers to engagement

We were very aware of the many practical barriers that people faced when taking part in research-related activities. We noted that it was difficult to schedule a time to speak where service users were free from the responsibilities or the demands of life stressors. Despite this, participants tried hard to accommodate our requests for interviews.

Our impression was that, entirely understandably, a significant time commitment to research did not feel like, or could not practically be, a priority in comparison with substantial everyday responsibilities, including caregiving responsibilities, and challenges. We understood that it would be hard for many clients to commit to a more involved or sustained role in research and to join regular meetings, if the committees and research meetings were set up in a conventional way. Therefore, an early learning point, was that this should be named and acknowledged, and that research engagement must be flexibly arranged around the schedules of EBEs in order to facilitate their optimal engagement. It is also important that EBEs are appropriately compensated for the extensive time and any emotional labour that they may be required to invest in research co-production or participation (although creativity in what compensation looks like may be required for those in receipt of government support or other benefits). See Faulkner and Rose 2021, for a clear exposition of the emotional labour required for involvement with, and co-production of, research into mental health.

Reflections on factors influencing the nature of engagement

Response bias

During the interviews, several survivors asked questions such as, ‘Is this the answer you want to hear?’ ‘Is this correct?’, and one said, ‘I am trying hard’. We wondered whether people felt able to express their opinions freely or felt able to say that they did not know the answers to our questions without feeling embarrassed, or whether they had concerns about providing constructive or negative feedback, for fear of being seen as criticising the service. Given that the organisation provides a wide range of support to service users we also considered whether they had agreed to take part in the study out of a sense of obligation or responsibility.

The ability of our service users to say ‘no’ to requests for participation is likely to be multiply determined. The control tactics used by traffickers and abusers can deplete an individual’s sense of agency (Hopper & Gonzalez, 2018). Restitution of this agency may take time, and it can lead to people struggling to refuse the demands of others. Moreover, the word ‘interview’ used in research may resemble Home Office interviews which might have made service users feel uncomfortable but also might have inadvertently further reinforced the notion that there was a ‘correct’ way to respond to the questions. This highlights the need for clear explanations about the nature and purpose of research, as well as the importance of language and terminology in research activities with this group of clients. The authors thought, with hindsight, that it might have been preferable to substitute the term ‘interview’ with ‘a meeting or discussion to find out what your thoughts about/experiences of X are’. In making this suggestion though, the authors recognise that this is another good example of an over-reliance upon a sole-researcher authorial viewpoint, and it would, again, have been better to have consulted EBE’s as co-producers to explore this further.

Talking about trauma

Although we did not ask people to discuss their history as part of our internal enquiry, being asked to discuss their own traumatic experiences as part of research activity was a topic that generated a marked divergence of views. We offer some reflections upon this below. Some service users expressed worries over the need to disclose or revisit the traumatic events they had experienced. This is consistent with other qualitative research which noted survivors expressing worries over possible re-traumatisation whilst sharing personal history of trauma and addiction (Edwards et al., 2021).

In contrast, one survivor mentioned explicitly that she was willing to share details of her past for research purposes despite it being very difficult, as 'silence will give the government and the traffickers permission'. This view is central to the notion of the value of giving testimony, where speaking out counters the oppression achieved by historically silencing survivors. It echoes the idea of emancipatory research in the psychiatric survivor movement (Faulkner, 2004).

Furthermore, past research from mental health service users, has noted that the aim to protect of service users from all harm within a research context could, at times, be patronising and inappropriate. Some people thought that participants might be distressed by the research interview but would still wish to contribute, highlighting that distress does not mean harm in certain circumstances (Faulkner, 2004).

Our view is that, it remains vital for researchers to value and to validate the refusal to discuss the past, as a personal choice, and to ensure that ethical procedures are carefully thought about when asking survivors of trauma about their traumatic experiences, whether directly or indirectly. This is of particular importance in research group settings where some people may be happy to share past traumatic experiences, but others may not wish to be exposed to this material. In group settings, it may be most helpful to ask potential participants whether they are comfortable in a) speaking about their own trauma-related material and b) hearing about trauma-related material from others as part of the study and to compose separate groups accordingly.

Recommendations

Based on our experience and reflections, we discuss some of our recommendations when engaging with survivors of trauma and human rights abuses in research.

1. Research priorities

It is important to note that the research priorities for the people that we spoke to were related to issues that affect them the most at the current time in the UK context, rather than issues more specifically connected to their traumatic experiences. For example, they highlighted accommodation and education/vocational needs, the impact of the lengthy asylum process and other hostile government policies but also the stigma associated with accessing mental health services and the mental health of stateless people as potential areas where research (and other forms of advocacy) were required. Services planning research studies should therefore consult with their EBE's as to the priority areas for research for their organisation.

2. Education about research aims and process

Understanding of what research is or can be varied very widely within this group. There is a clear need for researchers to explain the research vocabulary, purpose, process and implications to survivors more clearly. Researchers need to ensure that the research environment does not replicate any aspect of adversarial interview/interrogative techniques that survivors may have experienced in other contexts. A key element here is to offer potential participants as much choice and control over the manner of their participation as is possible. For example, service users should be offered choice as to where and how they participate in research (e.g. via email or phone or videoconferencing or in the organisation's space). Office settings should feel relaxed and be made comfortable, with options to sit on sofas with low tables or across desks/higher tables and a choice of refreshment should be provided. Service users expressed concerns over whether discussing their experiences in a research setting would impact on their asylum application, or if information would be shared with the Home Office. Potential participants may feel very worried indeed about making any remarks that could be construed as critical of the UK legal process, UK authorities, their legal representative or aspects of their life in the UK such as the conditions of their accommodation. We are aware that researchers being clear about how information was stored and processed may be common practice in research, and yet emphasis and repetition is needed with this group. Researchers should proactively emphasise where and how information will be shared and state explicitly that information will not be shared with the Home Office and or/be used as part of their asylum application where this is the case Informed consent.

3. Informed consent

Trauma-informed research requires careful consideration of the issues around consent. As mentioned above, service users' sense of agency and their ability to exercise choice may have been compromised by their experiences of abuse or other breaches of their human rights. As such, any consent procedure should make it clear that deciding not to take part is a valid choice, and that this choice is understood and respected by researchers (who will themselves have decided not to take part in research on many occasions). Furthermore, researchers should seek consent carefully again at the time of interview and be ready to offer alternative dates, and/or to provide reassurance on the validity of the right to withdraw at this, and any stage of the research. It is vitally important to recognise that there should be no expectation that people would want to discuss past traumas in a research context and that their agency over when, where and how and to whom they choose to revisit the past should be privileged and prioritised. A rich discussion of the ways in which facilitating choice for this participant group in research settings is beyond the scope of this paper, but it may be helpful, for example, to consider identifying a neutral third party that the participant can discuss the research with and say 'no' to if needed (such as a support worker or non-involved member of the organisation that the person feels at ease with). Researchers and organisations should also think carefully about how frequently they will chase-up service users who are not responsive to calls or messages asking them if they would be interested in participating in research projects – not responding to requests should be considered a response.

Given some survivors' experience of extreme disempowerment and human rights violations, the right to not answer questions, and to withdraw will need to be actively emphasised. We encourage researchers to appreciate the nuance and value of what it means for some service users to feel able to advocate for themselves and say 'no' to being involved in research.

4. Tackling engagement barriers and appropriate compensation

Service users told us that their efforts and contribution need to be valued and to be paid for. Researchers should be mindful that some people seeking asylum are prevented from engaging with paid work and alternative forms of renumeration (such as small value vouchers should be considered). The benefits of research to them, such as CV building, or support with developing their practice as co-researchers, needs to be realised practically by the organisation in all cases, but especially where payment is not possible. In the light of multiple practical needs and priorities, the means to engagement needs to be diversified. For example, some people mentioned they were more likely to respond to research questions via email than having a face-to-face focus group. On the other hand, others thought that having face-to-face groups with refreshments may motivate some to attend. Additionally, there may be concerns from service users about being in the same group with others from the same background due to stigma or fear of being identified. Researchers need to be mindful of these complexities and cultural considerations, and provide the option of one-to-one interviews and trusted interpreters. Even where the potential participant does not know the interpreter, the interpreter should be known to and trusted by the organisation. Unknown telephone interpreters should not be utilised, and the name of the interpreter should be provided to the client before they are used. Researchers should consider that interpreters may themselves by EBE's and that they can provide an invaluable service as cultural mediators alongside their linguistic expertise.

5. Investment in EBEs and their skill development

For service users who express an interest in becoming peer researchers, additional types of support are needed. These include practical support, which comprises research training, as well as administrative assistance (Faulkner, 2004) but also support with wellbeing. A service user described the importance of clinical supervision to support peer researchers' wellbeing, as their interviewees may share experiences that resemble their own, which could lead to the (re)emergence of trauma symptoms (See also Shankley et al., 2023). Service users told us that, as peer researchers, they would need to feel like they were part of the team, to not feel judged, and to be given appropriate supervision spaces. The ways in which co-producers may be properly supported by the research team will vary from organisation to organisation, but it may be helpful for an organisation to consider the needs of co-producers as they would for any staff member who is also an EBE.

Concluding thoughts

We hope that some of these reflections will be helpful to others undertaking research with survivors of trauma and human rights abuses. In summary, we recommend that researchers consider carefully the research priorities of service users, the nature and fluidity of the consent process and ensure the meaningful participation and inclusion of this population.

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