**“It's nice to be able to have the freedom to talk about how you feel when for so many years you've been squashed. But that's freedom as a woman to help other women”: Including families with experience of domestic violence in a longitudinal qualitative cohort study.**

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**Abstract**

Families with experience of domestic violence are under-represented in cohort studies and little is known about best practice for including them in longitudinal research. This paper explores barriers and enablers to participation in qualitative longitudinal research (QLR) for these families through in-depth semi-structured interviews (*n* = 16) with specialist practitioners and survivors. This paper analyses participants’ views on the benefits of taking part in QLR; and best practice for recruitment, retention and data collection with families that have experience of domestic violence in QLR. We propose that trusted relationships; flexibility and personalisation; and co-production with people with lived experience are crucial to enabling participation across all phases of research.

**Keywords**: qualitative longitudinal research; domestic violence; seldom-heard groups

**Introduction**

Despite a long tradition of qualitative longitudinal research (QLR) exploring lived experiences of some marginalised groups (McLeod & Thompson, 2009; Neale, 2020), and extensive literature on doing research with survivors of domestic violence (Downes, Kelly & Westmarland, 2014; Westmarland & Bows, 2018), there are very little evidence of qualitative longitudinal studies involving families that have experienced domestic violence (Torgerson et al., 2024). This is largely due to the many challenges involved in recruiting and retaining ‘hard to reach’ families (Deane & Degner, 1998) and concern for the complex ethical considerations of working with a potentially vulnerable group (Downes et al., 2014). In this paper we explore barriers to participation in research for these families, along with potential facilitators.

It is important to understand the barriers to participation that exist for families who have experienced domestic violence so that we can explore new ways of encouraging and supporting their participation in QLR. Longitudinal research would allow for a more holistic and expanded understanding of domestic violence (Downes et al., 2014). Addressing these barriers could lead to better knowledge being generated about these families’ lives in a longer-term perspective, including in relation to their children’s education and health, and can improve the experiences of families that have experienced domestic violence.

The research presented in this paper comes from a scoping study which focused on identifying barriers and facilitators to including families in which a parent has experienced domestic violence in QLR. The context for this is that the UK Economic and Social Research Council (ESRC) commissioned two scoping studies in 2023 to explore the feasibility of using a qualitative longitudinal approach to including seldom-heard families in a cohort study, including families that have experienced domestic violence. There is limited literature regarding the methodological challenges of recruiting these particular families and retaining them in QLR (Torgerson et al. 2024). In this study, we also had a specific focus on racially minoritised families, as they are among the least heard voices within this already-marginalised group.

The literature suggests that these families are seldom heard for a variety of reasons, including challenges with recruitment and retention e.g., the fluid and dynamic circumstances of survivors of domestic violence, competing life demands, not seeing the research as relevant to them, and a desire to move on with their lives (Deane & Degner, 1998; Shaughnessy, 2002; Van Wijk, 2014). Further factors contributing to attrition are lower incomes and lower education levels among this population, which are often related to their experiences of domestic violence (e.g., poorer physical and mental health) (Siddiqui, Flay & Hu, 1996; Van Wijk, 2014). It is also considered crucial to have experienced and specialist-trained researchers who understand the complexity of survivors’ experiences working with this population, and a failure to ensure this can present a barrier to continued engagement with research (Case et al., 2010; Patel, Docu, & Tennakoon, 2003). These challenges are relevant to recruiting these families into any study but are amplified when considering how to retain them in a longitudinal study.

A further consideration for including survivors in research is the need for data collection to be inclusive and accessible when many data collection approaches can be inflexible and therefore retraumatising (Westmarland & Bows, 2018, Van Wijk, 2014). Westmarland & Bows (2018) note that data collection with survivors must facilitate a better understanding of their perspectives, rather than aligning with the researchers’ own imaginings. While arts-based methods have been proposed as appropriate for working with survivors (Brady & Brown, 2013; Westmarland & Bows, 2018), our understanding of how these can be used within the context of a longitudinal study, where developmental, cognitive and other transitions will occur, is less well-developed.

As well as challenges related to recruitment, retention, and data collection the enhanced ethical scrutiny that working with survivors of domestic violence and their families’ entails is a significant consideration (Downes et al., 2014; Westmarland & Bows, 2018). Downes et al. (2014) suggest that even though the ethical challenges are significant, it is important to develop ethical, skilled researchers that are invested in protecting survivors from harm as well as in maximising their capacity for self-determination and autonomy. Understanding how to do this well over a prolonged period of time, and with due consideration to the fluid circumstances that survivors often experience, is vital for their inclusion in longitudinal research.

Westmarland and Bows (2018) note that while such issues present challenges to both families and researchers, these challenges are unlikely to be insurmountable, and can in fact have possible benefits to participants e.g., enabling self-reflection and facilitating access to support services. That said, in a systematic scoping review undertaken as part of this project it was notable that very little evidence was found of QLR with this population, suggesting the barriers are having a powerful effect on inclusive research practices (Torgerson et al., 2024).

Thus, while methods for doing QLR are well-established, as is knowledge about how to conduct research ethically and safely with survivors, there is little evidence of QLR with families that have experienced domestic violence. The current study attempts to fill this gap by speaking to survivors of domestic violence themselves, about the factors that would enable or hinder their families’ participation in a qualitative longitudinal study.

**Methods**

The overarching aim of the study was to explore best practice for engaging families that have experienced domestic violence, as they are often missed from longitudinal, or cohort, studies due to a perception that they are ‘hard to reach’ (Neale, 2016) or hard to include due to a complexity of needs and risks. In order to explore the experiences of this ‘seldom-heard group’ we adopted a qualitative and participatory approach to the study. A central methodological focus for the study was co-production of knowledge with participants who have lived experience of domestic violence, or experience of supporting survivors of domestic violence in a professional capacity.

The study sought to answer the following research questions: 1. How can we recruit families who have experienced domestic violence to QLR in an ethical, safe and respectful way? 2. How can we keep families who have experienced domestic violence engaged with QLR in an ethical, safe and respectful way? 3. How can we collect data from families who have experienced domestic violence engaged with QLR in an ethical, safe and respectful way? 4. What are the ethical considerations regarding data management, data sharing and data archiving for QLR with families who have experienced domestic violence?

*Participants*

Given our focus on co-production of knowledge with participants who have lived or professional experience of domestic violence, we employed the following inclusion criteria: 1. Parents who had experience of domestic violence (since becoming parents)

2. Practitioners who worked with adult survivors of domestic violence

3. Practitioners who worked with children who have experienced domestic violence

4. All participants were voluntarily participating in the study (the ethical processes we followed are described below)

All of our participants were based in the UK, due to the sampling strategy we employed (as described below). This was deemed appropriate because the knowledge generated from the study would be to inform a UK-based cohort study. However, we did have a particular focus on including knowledge from and about racially minoritised participants as they are typically under-represented in traditional cohort studies and in research about domestic violence.

**Characteristics of participants**

All of our participants self-defined as women in both the survivor and practitioner groups. Due to this being a vulnerable participant group, we did not collect personal category data such as age, ethnicity, sexuality etc. from our participants. However, we did work with participants who self-identified in interviews as racially minoritised and as having professional experience of working with racially minoritised survivors in particular.

*Sampling and Recruitment*

We used a purposive sampling strategy to recruit participants to this study. A primary facet of recruiting vulnerable and marginalised participants to research is the development of trusted relationships (reference). In order to facilitate this, we adopted a place-based approach to the study which focused our partnerships and recruitment in a particular region of the UK. We used purposive sampling within the place-based approach to recruit participants from more diverse areas within this region. We worked in collaboration with two specific third-sector organisations that provide specialist support to adult and child survivors of domestic violence (a regional organisation, and a national organisation, respectively). The regional specialist charity is based in a diverse region of the UK, in terms of socio-economic and ethnic mix, and it therefore provides support to survivors from a wide range of socio-economic, ethnic, cultural and linguistic backgrounds. The national domestic violence charity provides specialist support to adults as well as children who have been affected by domestic violence. It takes an intersectional perspective to domestic abuse, including forced marriages and honour-based abuse in its definitions, support and training for practitioners. Therefore, both organisations were well-positioned to help us to recruit a diverse group of participants, including practitioners with knowledge about working with racially minoritised survivors.

All of our participants were contacted through these organisations rather than by direct approach from members of the research team. We interviewed 16 participants in total; five were parents who had experienced domestic violence, and 11 were practitioners who provide specialist support to adult and/or child survivors of domestic violence. From our initial sample of 20 participants, we had attrition of two practitioners (who could not take part due to work commitments) and two survivors (who did not reply to invitations to participate).

*Procedure*

We used semi-structured interviews to explore practitioner and survivor perspectives on ethical, safe and respectful research practices for working with families who have experienced domestic violence in QLR. The interview schedule was structured around our four research questions relating to recruitment, retention, data collection, and the ethics of data management.

Participants were offered an in-person or online (Zoom) interview in a location and at a time that was convenient to them. All interviews were conducted by the project researcher (second author). Interviews were audio-recorded and professionally transcribed. Following transcription all participants were given the opportunity to review and comment on their transcript.

*Analysis*

The analysis of interviews was underpinned by a phenomenological approach in which we sought to understand the experience of participating in QLR from our participants’ perspectives. Interviews were analysed thematically using template analysis methodology (Pandey, 2016; Brooks et al., 2015). An initial coding template was developed with *a priori* themes based on data subsets that mapped onto the semi-structured interview schedule. Both authors independently coded the full transcripts from each participant group using the initial template and added potential codes to each of the themes. The authors then jointly assessed the discrepancies in their thematic coding and developed a new version of the template to reflect a joint interpretation of the data. This cycle continued until all transcripts had been coded. In total there were four iterations of the template before the final version was agreed.
In the presentation of findings that follows, quotes attributed to practitioners are given a code beginning with ‘P’ and those attributed to survivors are designated with an ‘S’.

*Ethical considerations*

The Ethics Committee of the researchers’ university department approved the study (Ref: 23/24 Data protection registration number: Z4855807). The researchers have extensive academic and practitioner experience of working with survivors of sexual harassment and domestic violence. All participants were sent a project information sheet and consent form via the specialist organisations. One organisation also commented on project documentation before it was shared with potential participants. In addition, the research team developed individual safety plans with each participant for how to manage distress, the need for breaks, or wanting to end participation within the interview itself, as well as signposting to local and relevant sources of support following each interview. The second author, who conducted the interviews, has specialist training in managing distress and handling sensitive disclosures. A central focus of this study was to understand how ethics, respect and safety could be embedded into research processes from the perspective of survivors of domestic violence. The knowledge generated through interviews informed our ongoing research practice throughout the study.

**Findings**

Our analysis allowed us to describe participants’ views on best practice for including families who have experienced domestic violence in QLR. Our focus in this paper is on the inclusion of adult survivors (rather than child participants) in this type of research. We focus in particular on their views regarding the benefits of participation in QLR; recruitment; retention; and data collection. We note that the ethics of doing research with survivors have been written about in detail elsewhere (e.g., Westmarland & Bows, 2018). For longitudinal research, issues of data storage and sharing over time, and archiving are particularly relevant. We do not cover these issues here, as our participants’ views suggested that further and more extensive exploration of these issues is needed.

**Theme 1: Benefits of including families that have experienced domestic violence in qualitative longitudinal research.**

Survivors and professionals who worked with survivors of domestic violence felt strongly that there were clear benefits to these families of taking part in longitudinal research about their life experiences. The two main benefits that were identified across both groups of participants were being better able to understand and validate their own experiences and increasing societal understanding and awareness of domestic violence.

*Opportunity to be heard*

Survivors said that participation in a longitudinal research study about their life experiences would be empowering for them as it would give them an opportunity to be heard. Adult survivors might have experienced being disbelieved in a range of professional settings, or having a particular narrative talked about them. It would give them an opportunity to voice their own narrative about their experiences and to share with a non-judgmental listener about how they feel about their own lives.

*It's nice to be able to have the freedom to talk about how you feel when for so many years you've been squashed. You've been told you can't feel this, you can't say this, you can't… and that's freedom. But that's freedom as a woman to help other women. That's not just to live your life. That's to share your story and help other people. (S1003)*

Practitioners working with survivors also said that being given the opportunity to have their lives represented alongside those of other families could be experienced as empowering, as survivors are often marginalised in a variety of contexts.

*I feel that a lot of our survivors’ voices get lost sometimes, their experiences aren’t always heard. We will get asked, you know, I will get asked personally or as a professional, like, “Why am I going through this process, why am I not believed, why is this so difficult?” [...]I think [...]people struggle to, they feel like other professionals don’t understand their experiences, or are not understanding of the reason why. (P1004)*

It also gives participants the opportunity to feel less isolated in their experiences, and less negatively ‘othered’, especially if the focus of the research is a more holistic understanding of their lives, not simply defining them by the violence they have experienced. This was the case in particular for racially minoritised survivors, whose experiences are not represented or sought out to inform narratives or understandings about domestic violence, or support given to survivors.

*I suppose it’s that sharing their stories to help other ethnic minorities, we don’t usually hear our voices in mainstream as much. It’s usually, you know, it’s still…there’s still that narrative of the victim is the feeble little woman and the abuser is the big, angry man, and that’s what we get. (P1007)*

Further, the inclusion of marginalised perspectives could benefit professionals working within these communities, as they may feel ill-equipped to approach survivors or less knowledgeable about the specific impacts of domestic violence for some racially minoritised women.

*You don’t, you wouldn’t hear those stories typically, and that being counted as domestic abuse, because there’s a lot of, “Well, that’s in their culture. We don’t want to say anything because we don’t know enough about it. I don’t want to get accused of being racist, so therefore I don’t want to say anything, and we’ll just ignore that because we don’t know enough.” And actually, the benefit is to encourage and educate people that actually, you can ask questions, you should still be asking questions and you’re entitled to do so, and sharing those stories as well, and in turn, potentially getting more tailored support. (P1007)*

*Understanding own experience*

Survivors and professionals also felt that participation in a longitudinal study would help them to understand their experiences and the impact of domestic violence in their lives. It could help to understand the cyclical nature of their experience as well as the longer-term, less visible impacts of domestic violence in their lives. Several practitioners pointed out that being able to reflect on their experiences and what they have overcome over time could be very positive for survivors.

*So, I suppose that longitudinal study captures all of that, the journey an adult takes, the journey the children take, when living in an abusive situation, fleeing, but then actually moving on, empowering to make life different…kind of different life choices that they’ve had to make then, you know, have the best outcome for their children and all those kind of things (P1007)*

Participating in a longitudinal study that is focused on their family’s life in a more general sense would bring the benefit of developing an identity that is not solely defined by their experiences of violence. This is a key pillar of a trauma-informed approach to working with survivors of domestic violence.

*I think it’s about an opportunity to say how you are thriving or what you found difficult, and that can be addressed. (S1005)*

*Increasing societal awareness and understanding*

Participants felt that a clear benefit of including families with experience of domestic violence in longitudinal research is the contribution they can make to increasing societal understanding about domestic violence. The benefits relate to understanding the longer-term impact of domestic violence, making life better for other families, dispelling myths about domestic violence, and gaining knowledge that can be used to improve practice.

*I think it’ll be good to see in the long-term how children who’ve grown up in those households where they’ve been subjected to that how they do adapt and cope (P1005).*

For racially minoritised families, there was a sense that practitioners (e.g., social workers) are not always aware of the cultural differences that compound stigma or that present additional barriers to exiting an abusive relationship. The fact that extended families may sometimes be perpetuating or enabling abusive behaviours is not always understood and the potential of a longitudinal study to generate better understanding was seen as valuable in this regard too.

*So just being really sensitive of our language, the cultural differences and making sure we’re not causing offence, we’re not insensitive, we understand what we’re going to ask, and we understand that culture before we launch in and ask questions, because you’re just going to put off people if they feel like, you know, they’re not being understood. From a diversity perspective, I’d say they’re the most important things. (P1007)*

The knowledge that could be generated could therefore also help to inform agencies and services working with survivors, including an improved understanding of what is needed for effective cross-agency working.

**Theme 2: Recruiting families that have experienced domestic violence to longitudinal research.**

Participants emphasised the need for recruitment methods to be trauma-informed, survivor-led, flexible and transparent. Survivor-led recruitment methods included those that take account of the routes through which contact to participants is made; transparency about the purpose of the study in recruitment materials; the timing of recruitment; and the potential risks in relation to trauma and shame.

*Trusted relationships*

The importance of working with trusted organisations, especially those with specialist expertise in supporting survivors was clear across interviews with participants. This confirms existing literature on working with participants who have experienced abuse of any kind (Case et al., 2010). Working with organisations that have an existing relationship with families was seen as important for recruiting children as well as adult survivors, as this would enable the research team to assess potential risks to participants and would have the additional benefit of children actively receiving support around participation in the study.

*I think probably through the support systems that they've already got because it's people that you trust and you know that they've got good intentions. (S1001).*

There was a clear steer away from working through organisations such as social care or the police, where there was a perception of risk and of being viewed through a negative lens.

One suggestion was to co-create a communications plan with a participant advisory panel that would allow recruitment through multiple avenues, including secure online fora. This could help to reduce the risk of missing participants from different cultural and religious communities, or those who are not actively receiving support from specialist organisations. This aligns with Westmarland & Bows (2018) who note that successful recruitment of domestic violence survivors necessitates contact through a range of contexts, including public toilets, community clinics, cafes and targeted social media posts.

*I would always advise looking at co-creating that kind of comms plan and reach plan because those representatives from those groups are the ones that will be able to tell you how to reach those more complex hidden voices or invisible voices, and I would therefore have an expert advisory panel which are made solely of survivors. (P2003)*

Related to the need to use multiple routes of contact in order to capture a wide range of survivors was the need to be mindful of intersectionality in survivor experiences more generally. Practitioners talked about the need to make recruitment materials and project information available to a wide range of survivors, including in different formats and in multiple languages. Some routes of contact - if used in isolation- might be limited in terms of the perspectives that could be captured and could even pose a further risk to a survivor as captured in the quote below. Specialist organisations with a detailed knowledge of the local community could signpost to alternative means of contact.

*If you’re going to be talking to ethnic minorities where English isn’t their first language, how are you going to do that? Are you using an interpreter? So from personal experience, interpreters are…it’s difficult, it can be a really difficult conversation, because it doesn’t flow like our conversation’s flowing, you know. And sometimes, again, with honour-based abuse cases in particular, if there is a notion of what honour is and what dishonour is, then if you get someone from the same community, there is the chance that that person might know the family, or even if they don’t, if they belong, have a similar honour code or belong to a similar community. (P1007)*

*Clear and transparent communication*

Being transparent and clear about the purpose and scope of the study, as well as the requirements of participants, was important to families feeling safe and feeling able to participate in the study. McKenzie et al (1999) similarly found that regular updates regarding the goals of the research and the importance of participants’ contribution to reaching these goals is important to encouraging participation in QLR.

Specifically thinking about survivors, clear communication about how their safety would be ensured was also vital, including with regard to how initial contact is made, how follow-up conversations or contact are initiated, and how participants could communicate with the research team. The idea of having a consistent contact point for families participating in longitudinal studies was frequently mentioned by survivors.

*I think the sort of personal approach like the one to one where we emailed a bit first to build that up so you know it's sort of genuine, it's not coming from lots of different people. It's having that one to one contact. I think that does help. (S1001)*

Practitioners said that research teams would also need to be completely transparent about what is required of participants, what the likely time commitment would be, how participation would take place (e.g., where, how often, with whom), and what the expectations of participants would be. A further point here was that the anticipated outcomes of participation should be clearly communicated to potential participants, so they know how their data is going to be used.

 *I think it is that fear and lack of trust knowing who the people are at the other end, knowing sort of where that information is going to go and what it's going to lead to. So, as much information around where it's going to go and what the outcome is going to be really to give them that security so they know what they're aiming for, where it's all leading to. (S1001)*

*Timing of contact/recruitment*

While cross-sectional studies tend to ask survivors about their experiences of violence in the past year (WHO, 2016), practitioners in our study were unanimous in their view that contacting survivors within a year of their most recent experience of domestic violence could present a risk to participants in several ways, as they would likely be in crisis or trauma mode. This would have two likely impacts for participation: firstly, they would not be well placed to contribute meaningfully to a research study, or to stay involved with it over a prolonged period. Secondly, participation could be psychologically harmful if they were still in a very vulnerable position. Safety-wise, there might be an increased risk of perpetrators still being closely involved with families in this relatively early period following domestic violence. Survivors in the study noted the need for flexibility and a personalised approach in relation to timing of contact; for some participants a year after their most recent experience would be too early to participate, while for others a shorter - or even a longer - time period before contact regarding recruitment might be appropriate.

*You know, well, like I’ve said, we were rescued in 2006, so I can get you need criteria which you’ve got [use for research purposes], I understand that, but I think that’s probably a bit too narrow. And if somebody’s not ready then and then offer them, say, “Shall we come back to you in a year?” or open it to them, because we don’t know how long your study’s going on, that they could contact you, saying, “Do you know what? Something’s happened in my life that I am absolutely ready to do it now”. It’s a tricky… there isn’t a one-size-fits-all answer, is there, to this one? (S1005)*

One practitioner also said that it might be confusing for participants to be involved actively with a support organisation as well as with a research team, so perhaps participation could be offered as they are coming to the end of their involvement with a service.

*Trauma and shame*

Some of the barriers to recruitment that were raised included trauma and shame on the part of participants, including fear of revisiting their experiences of abuse.

*The barriers to recruiting? A lot of people are ashamed about what they've experienced and what they've gone through. We go back to that feeling of blame. (P1002)*

Survivors noted that a barrier to parents’ participation might be guilt or shame around their children having been exposed to violence. Parents may be worried about their children being exposed to memories or information relating to their domestic violence experiences, and this was made more complex by the fact that not all children will recognise what they have experienced as violence or abuse. Practitioners noted that shame, guilt and trauma may have led to silence around the violence experiences within the family, and this might put parents off allowing their children to participate in interviews about their family life. Conversely, child participants may try to protect their parents in terms of what they say to researchers, due to internalised shame or ongoing trauma.

*Parents could be one barrier (to recruiting children) because maybe their young person doesn’t know that much about what’s happened, or they like to think that they don’t know that much about what’s happened. (P2004)*

These are important factors for researchers to bear in mind when designing recruitment materials that are survivor-led and using a trauma-informed approach. The unique experiences of this participant group mean that concerns around how and when contact is made will vary over a prolonged period of time.

**Theme 3: Retention of families who have experienced domestic violence engaged in longitudinal research**

Survivors and practitioners were asked about factors that might influence engagement with and retention in a qualitative longitudinal study. Participants had clear views on factors that would be important to motivating these families to stay engaged with the study, and risks or barriers for research teams to consider. These were the need for regular, personalised contact; relationship building and trust; considerations of safety; co-production of knowledge; and incentives.

*Contact*

Frequency of contact was an important factor in keeping families engaged with, interested in, and motivated to participate in a longitudinal study. A key learning here was to be participant-led in planning the regularity of contact, as this might be variable depending on participant’s circumstances, their age (adult or child) (*Again, it's person by person. I think the best would be to, if there was an option of saying to them how often do you want? (P1001*) For some participants, informal contact in between research encounters was important in order to build strong and enduring relationships between participants and research teams. Previous research on retention in longitudinal studies has noted the importance of informal points of contact such as friendly emails (Van Wijk, 2014). However, a key point that was made for this particular population was the need for flexibility and adaptability regarding communication and frequency of contact to the individual family. For some families, regular, informal opportunities to meet or be in contact with the research team would be helpful; for others, this might feel intrusive. The necessity of a trauma-informed approach was highlighted again, with the survivor’s needs leading the approach to be taken.

*Does it have to be the same for everybody? Because one thing I would say is if you’re going to be trauma-informed, if you’re going to be DV-informed, let the client lead how often they want to be in contact and how much time they can provide into doing that. (P1007)*

*Relationship building and trust*

A theme that ran throughout participants’ conversations about retention and engagement of families that had experienced domestic violence in a longitudinal study was the importance of relationship building and trust between the research team and the participant. The value of informal contact was emphasised by practitioners as a means of relationship building. Examples of this included taking participants for a coffee, sending updates about the project, allowing older children and adults an opportunity to just chat and vent during and between research contacts.

The need to build up trust in order to keep participants motivated, as well as to reduce the risk of re-traumatisation was also a prominent theme.

*But I think it's that building that trust, isn't it? Building that relationship. So, I think you would get more value, they would feel, from my experience, they would feel unsettled with somebody different. (P1002)*

Survivors talked about the need to be seen as a real person, not just a ‘participant’ with an allocated study number. The feeling of being valued as a person beyond their experience of domestic violence was also viewed as important. This was linked to the need for consistent and trustworthy relationships with the research team, and not having to ‘start over’ with a new researcher at every contact. This consistency would also avoid the need to repeat their story or experience, which could be re-traumatising.

*Rather than just a number in a study, if that makes sense, that you're not just Number 59. That well, I'm going to ring Number 59 today or Number 6. No, it’s “I'm going to contact Claire today”. I think that would be really important that actually they're seeing you as a person, not just a survivor, but as the person that has survived. (S1001)*

*Safety across time*

Maintaining participant safety was a crucial factor in keeping participants engaged with a longitudinal study. Safety was talked about in terms of practical and physical safety, as well as in terms of psychological safety. It was widely agreed that with families who have experienced domestic violence, circumstances might change rapidly and markedly over a prolonged period of time. In terms of physical safety, many professionals noted that it would be crucial to have a clearly defined plan of action for survivors who were still in abusive relationships, or if contact with a perpetrator was resumed. This could include a safety plan, as well as a plan for future participation in the study.

Understanding the cyclical nature of abusive relationships was also seen as important, in particular recognising that people might re-enter abusive relationships months or years after exiting them. This highlighted the need for establishing safe methods of continued contact over a prolonged period of time, in close partnership with the survivor.

*We have to check whether email’s safe, whether their partner has access, whether their phone’s safe, whether we can leave voicemails, whether we can text. And if you're having irregular contact as in if you're having a year between it, people change their numbers, people change this information quite often, especially in an abusive relationship. (P1001)*

One strategy that has been suggested for keeping in contact with survivors safely in the existing literature and that was suggested in this study too, was to agree on a ‘safe contacts’ list. Previous studies suggest including close friends, neighbours or family contacts provided by the survivor (McFarlane, 2007) . However a number of practitioners suggested that a ‘neutral’ safe person such as an independent domestic violence adviser (IDVA) might be an important contact to include, precisely because within a cycle of abuse over time, close personal relationships might change from being safe to being risky. Survivors’ perspectives also confirmed the often-fluid nature of risk and the fluctuating status of ‘safety’ - both physical and psychological.

 *Yes. It goes back to that risk is so fluid and someone might be safe on a Monday, but she might not be on a Wednesday. You know, so, it's how you would work that. But perhaps you could have like the IDVA or the ISVA or the children's worker, whoever has that safe contact (P1002)*

Practitioners also recommended that a shared code be co-created between the researcher and the survivor in order to ensure that the person being contacted is a legitimate safe contact.

*Co-creation and contribution to knowledge*

Co-creation between the research team and participants at every stage of the study was thought to be important to retention in a longitudinal study. Working with a participant advisory panel to co-create recruitment strategies, incentivisation, data collection methods, retention strategies, and dissemination was considered useful in two ways: success in keeping families involved in the study, and making families feel that they are making a difference through their participation.

*I think knowing what’s happening with the research so if you’ve published things to show them those, if someone’s doing a little bit of policy work or advocacy work or anything like that. They come up against a lot of barriers in terms of society, in terms of family courts, in terms of other professionals not understanding what they’re going through so any time that what they’re doing is actually resulting in action I think that would really help them. (P1005)*

By working with participants throughout the research process, the safety of participants could be placed at the centre. This would facilitate ongoing participation over a prolonged period of time. Ongoing reminders about the anticipated outcome of their participation, including the difference they are making to knowledge, research practice, inclusion and so on were considered important to making participants feel valued - and therefore more invested in continuing in the study. This has also been noted as a successful strategy for other vulnerable populations (Van Wijk, 2014).

*You know, our words aren’t just going somewhere and nobody’s looking at it, it’s doing something. Or maybe even it’s like we’ve enabled this to happen because of this research so far, so little updates and things like that. (S1005)*

*Incentives*

In terms of incentivisation to stay engaged with a longitudinal study, the key theme was optionality and flexibility. There did not seem to be consensus about any particular kind of voucher that would be most attractive to participants; however, offering choice, and where possible, tailoring (for example, to suit a young person’s or child’s age or interests) of incentives was considered good practice.

*I think possibly a selection because again it depends on people's situations. Some people in sort of like my situation, they’ve been left with nothing. You know, they're struggling to feed their kids or they're struggling to put fuel in their car to get to work. Whereas other people might not be in that situation, they might not really need anything on a day-to-day basis and just want to go and treat themselves, that actually this is something for me. (S1001)*

There was some divergence of opinion in relation to whether vouchers might promote engagement, or whether they could encourage instrumental participation. Existing research suggests a lack of consensus about monetary incentives, with concerns expressed about the potentially coercive nature of financial incentives for low-income families (Moore, 1997). Some practitioners suggested that one incentive could be provided annually, rather than something at every research contact. Others suggested that a combination of incentives - focused on relationship building - could be used and might be more important than receiving something material in return for participation. For example, taking participants for a coffee or a light meal on some occasions, and providing a meal voucher or a gift card on other occasions.

*Change factors that might impact retention*

Change - and the need to be adaptable and flexible to change - was one of the most prominent factors discussed in relation to keeping families engaged within a longitudinal study. Participants noted how important it would be for the longitudinal element of the study to capture the amount of change that participants might experience in home/family circumstances and what societal changes might occur. There were three main domains of change: change to relationships and life circumstances over time; change for children and young people across the span of the study; and changing relationships between the participant and the research team over time.

Practitioners noted that the dynamics of domestic violence were unpredictable and that relationships might be fluid and changeable. Retention in a longitudinal study might therefore be impacted by participants entering a new abusive relationship and feeling shame, or by participants re-entering their previous abusive relationship and feeling unsafe to continue participation. The rapidly changing life circumstances of this particular group might also be a barrier to continued participation in a longitudinal study; this included having to move, navigating interactions with authorities e.g., the criminal justice system or social workers.

*Again, I think it depends on the survivor and what they're going through because obviously if they've got court cases and stuff in the beginning, things might change quite quickly for them. Whereas in the longer-term, it might start to reduce. So, again, maybe giving people those options that you can do once a month, once every three months, once every six, you know, and sort of tailor it really. (S1001)*

Participants might also feel that they want to move on from their experience and that continued participation in a study of their lives is an unwanted reminder of their past experiences.

*Sometimes, again, if they feel like they’ve had counselling or they’re able to put that behind them, they may not be wanting to be brought back and talk about it again and again. So, I suppose the longer it is, the more chance you’ve got of people then saying, “Actually, I don’t want to be a part of it.” (P1007)*

The lives of children change dramatically over a prolonged period of time for any population, and for this seldom-heard group, there are additional change factors to consider. These include changes in family circumstances (e.g. break-up of parental relationships; re-introduction of an abusive parent), living situation (e.g. having to move away from home to temporary accommodation), and educational situation (e.g. having to move between different schools). These factors may also impact negatively on social relationships, such as friendships within and outside of school. All of these factors might impact on a child or young person’s engagement with a longitudinal research study.

Lastly, the relationship between participants and the research team may change over time. This might be especially pertinent for child participants as they go through developmental transitions and become less engaged with the study and the research team. Another aspect to this is the changes to staffing that will occur within the research team itself over a prolonged period, and the impact that this might have on participants’ motivation to stay within the study, given the importance of trusted relationships to retention.

**Theme 3: Collecting data from families who have experienced domestic violence**

Participants’ responses regarding how best to collect data from families who have experienced domestic violence centred around three main themes. These were survivor-led approaches; a toolbox of methods; and considerations to safety.

*Survivor-led approaches*

Approaches that were led by the needs of the survivor and that were aimed at building trust were foregrounded in participants’ responses. As domestic violence can have lasting effects on survivors’ functioning and wellbeing (SAMHSA, 2014), it can be defined as a form of trauma. Taking a trauma-informed approach entails taking account of the specific needs that survivors may have as a result of the trauma they have experienced. This can relate to trust, transparency, communication, relationship-building and environment (Westmarland & Bows, 2018). Within a trauma-informed approach, flexibility is an underlying principle. Flexibility should be interpreted as an approach that is open enough to be sensitive to the changing needs and circumstances that historical or ongoing trauma creates for this group of participants. Participants noted that flexibility might be employed in relation to communication (the way in which information about the project and participation is given to the participant); offering different locations for interviews (e.g. cafe, home, outdoor space); offering different methodologies (e.g. walking interview, seated in a closed space; seated in an open space); being able to adapt the methods used to enable the participant to participate comfortably and feel heard (e.g. the use of creative methods; the use of resources as prompts; structured topics; adapting number of questions for children); and relatedly, reassurance that participants can opt out of different aspects of data collection.

In this study, practitioners clearly advocated for a survivor-led or trauma-informed approach to be taken in data collection. This approach should be used from the initial stages of data collection. Practitioners advocated for asking participants whether they would like to see interview questions or the topics to be discussed in an interview in advance (also recommended by Westmarland & Bows, 2018). Here, a key message was that a ‘one-size-fits-all’ approach would not be appropriate and that being led by the survivor’s needs was crucial.

*I think we need to be trauma-informed, we need to understand people’s experiences, and we need to understand that people, we’re connecting people with very similar experiences and both could react or cope very differently with their experiences, and it’s working out that individual person’s needs and the best way for them to be able to cope, isn’t it, and the safest way as well for people, because we don’t want to retraumatise people...So I think it’s just listening to what people say. (P1004)*

Within the research encounter itself, practitioners noted that being attuned to the participant in terms of the environment created; body language, spoken language, the form of questioning and active listening was vital.

The importance of collaborating with the survivor to ensure the research encounter is taking place in an environment that feels safe and comfortable was highlighted. This included clarity about the researcher’s role in the encounter (e.g., that they are there to listen and understand rather than to evaluate or judge); reiterating the confidentiality of the research encounter and assuring the participant of their anonymity in any reporting of the data; building trust so the participant is able to talk to the researcher honestly and without fear.

*Yeah, I do think, yeah, I think that's important, isn't it? Yeah, somewhere neutral. Somewhere where no one knows what you're talking about. You could be talking about anything. But I think after what you go through you do feel, you have got to feel safe, secure, private, looked after. (S1003)*

Related to the safety of the environment were considerations around responsive and reflexive body language, physical positioning and the use of language that mirrors the participants' own terminology around their experiences. Survivors placed particular emphasis on not solely defining them by their experiences of domestic violence and avoiding a deficit model in questioning about their lives e.g. asking open questions about their lives, rather than focusing on what ‘went wrong’. Relatedly, practitioners emphasised that having an awareness of the power imbalance in the researcher-participant relationship and working to redress this in the interactions was key. This could includethe importance of active listening, even when a semi-structured interview schedule is being used. Allowing for meaningful decision-making, such as when to pause, allowing for ‘venting’, and enabling the participant to control the way their experiences are narrated were also important ways to redress the power imbalance and to build trust.

Finally, the idea that participants could support each other throughout the study was also raised. Within a trauma-informed approach, recognising and building on individuals’ strengths and experiences as a way to promote recovery is important (SAMHSA, 2014). This might look like a facilitated support group for a cohort of participants in order for them to feel connected to a similar set of participants, as well as for them to share resources, strategies or experiences of recovery. This would support the principles of peer support and empowerment that are central to a trauma-informed approach.

*A toolbox of methods*

Participants noted that a toolbox of methods should be available to collect data from this particular seldom-heard group. Again, flexibility - having a range of suitable (co-created) options for survivors to choose from - was prioritised. These included a range of creative methods, which offered an ‘*alternative to just talking*’ (P1003). Suggestions included mood boards to be filled with photographs, words, magazine clippings to illustrate key moments over a specified period of time; journals and diaries (these could be written or include ‘doodles’); emoji boards and picture scales for young children; quotes or songs that represent feelings or capture experiences.

Journals and diaries were seen as particularly useful methods for capturing the fluid circumstances of families that have experienced domestic violence. It was also viewed as a less confronting way of eliciting information and could have benefits for participants too in allowing them to reflect on their experiences and ‘get things out of [their] head[s]’. As has been suggested by others (Brady & Brown, 2013; Westmarland & Bows, 2018), photographs were viewed as an important way to allow participants to access old memories and experiences as well as to represent their own experiences in different ways. Arts-based methods were seen as important to helping participants to relax and therefore feel comfortable to talk about their lives. These activities could be engaged with alongside a conversation to make the encounter feel more natural and less confrontational e.g. drawing, crafting, or having objects for participants to fidget with or hold.

*[...]Like when I start a session, I'll just lay lots of things out, whether that's some paper, pens, fidget toys, anything like that. And usually, you'll find they'll pick them up and start drawing, and then they'll start talking. So, even if it's not, that's the way you're going to collect the information... (P2002)*

In spite of the emphasis on creative methods, interviews were also seen as a useful way to gather information by professionals and survivors. One-to-one interviews in particular could help to establish a relationship with the researcher and would give participants the opportunity to share their own stories. As Westmarland & Bows (2018) have also noted they can be important for a conversational approach that allows the survivor’s voice to come to the fore. This was seen as key to keeping participants engaged in the study too. Considerations regarding environment, body language and terminology were highlighted as important within the context of interviews in particular.

Generally speaking, there was consensus among participants that the more creative the approaches used, the better. A toolbox of options should be available to allow for more participant choice and control and that multi-modal data collection would work best in this regard.

*I think that's a really good plan because I think often with interviewing spoken word is so hard when you, with these sorts of experiences, with the kind of training that goes with coercive control, speaking out is not allowed. It doesn't feel safe. I think to have the opportunity to explore what is in there, what is trapped in there in a creative way, just as many different portals in would be so helpful, I really do. (S1004)*

*Safe research encounters*

Safety was an underpinning concern across all phases of the research process. However, the importance of safety for participants and researchers within the research encounter itself was raised by a number of participants. For survivors, this related to their safety in terms of managing information about the study e.g., who they were meeting or who they were speaking to, especially if they were still living with a perpetrator. There were also concerns about safety raised in relation to some methods being potentially re-traumatising, such as family photographs, which might include images of current or former perpetrators of abuse. Photographs of particular locations might equally bring up traumatic memories. For children, conversations or activities that involve reflecting on family life might trigger memories that could make them anxious or distressed.

*I suppose photos can be triggering and photos- I suppose they’re choosing them aren’t they, but in order to choose the photos they might have to sift through a load of photos that have - got to be blunt - his picture, you know? Because they might be like, “Oh, I want to get a picture of my kids when they were that age,” and talk about them or something or, “That holiday that we went on,” or whatever and then… so it could be a bit triggering. (P1005)*

These concerns linked to a related safety challenge for researchers in managing different forms of data which might detail violence in some form. For example, drawings might identify family members, or diary information might include detail relating to violence. Safety was raised as a key concern in relation to management of this data, but also in relation to the researcher’s psychological wellbeing. However, the importance of having a toolbox of different methods available, including creative and visual methods, was highlighted throughout practitioners’ and survivors’ interviews.

**Conclusion**

This paper presented the findings of a scoping study to identify best practice for including families who have experienced domestic violence in longitudinal research studies. The key areas of best practice relate to benefits to the participants and recruitment; retention in studies over a long period of time; and data collection methods.

We propose that three key principles should be woven through future studies of this kind, with seldom-heard groups, including families with experience of domestic violence. These are: building trusted relationships; flexibility and personalised approaches in all aspects; co-production with participants with lived experience. These principles relate to all stages of research, from recruitment to dissemination of findings.

While this paper presents novel findings that have important implications for designing inclusive research, the current study has some limitations. Firstly, it is relatively limited in terms of sample size (n=16). We were able to identify clear common themes across participants and between the two groups (practitioners and survivors) but a larger sample would have improved the reliability of our findings. Secondly, within the sample, we had limited diversity in relation to participant characteristics. In particular we had a focus on racially minoritised survivors as they are under-represented in longitudinal research and in research on domestic violence. Only one of our participants self-defined as racially minoritised. However, several of our practitioners had worked with diverse populations and were able to make recommendations about the specific, intersectional issues that would need to be considered in designing longitudinal research with this group. Finally, while the focus of our study was on seldom-heard groups it is unlikely that we recruited the least heard people within this particular group. We recommend that future studies should pay particular attention to the experiences of the most marginalised people within seldom-heard groups, including racially minoritised survivors, LGBTQ+ survivors and disabled survivors.

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