"To be able to use my own experiences and turn something really negative into something hopefully that will be a positive thing for other women, to help improve services and to help inform research, that's just amazing it's helped me in my recovery as well".

(WEAVER member)

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An Australian Framework for the ethical co-production of research and evaluation with victim survivors of domestic, family, and sexual violence.

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An Australian Framework for the ethical co-production of research and evaluation with victim survivors of domestic, family, and sexual violence.

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Introduction

Evidence suggests that victim survivors of domestic, family and sexual violence often describe feeling silenced not only by the person using violence but also the service system and society more broadly (Ahrens, 2006; Hague, Mullender, & Aris, 2003; Pokharel, Hegadoren, & Papathanassoglou, 2020). Capturing the experiences, and voices of victim survivors through research has been seen as one way to increase understanding and awareness (Testa, Livingston, & Vanzile-Tamsen, 2011). However in recent years there has been increased interest in exploring more participatory and co-produced research and evaluation methods in the domestic, family and sexual violence fields. (Ragavan, Thomas, Fulambarker, Zaricor, Goodman, & Bair-Merritt, 2018; Yuan, Gaines, Jones, Rodriguez, Hamilton, & Kinnish, 2016).

This document outlines a Framework for the ethical co-production of research with victim survivors of domestic, family and sexual violence. It includes information about how the Framework was developed and provides a set of resources to support researchers and victim survivors wanting to engage in co-produced research and evaluations. It draws upon relevant existing guidelines and literature as well as previous work and experiences of the WEAVERs (see below) and University researchers who have been engaging in this type of co-produced research together since 2016.

The Framework was co-produced by academic researchers from the University of Melbourne Safer Families Centre and Lula Dembele, Fiona and Nina who are victim survivor co-researchers from the University's WEAVERs group. Input was also obtained from other University of Melbourne researchers across areas of mental health, social work, domestic and family violence fields. Valuable feedback was also obtained through an online survey and through workshops with key stakeholders.

The WEAVERs lived experience and victim survivor co-researchers

The WEAVERs are a group of women who have experienced domestic, family and sexual violence who play a role in 'weaving' lived experience into research, evaluation and training at the University of Melbourne. Members come from a range of backgrounds and may have lived experience of violence from their family and/or an intimate partner.

The WEAVERs group was established to ensure the voices of women and children who have experienced domestic, family and sexual violence would shape the work and agenda of university researchers, and influence teaching.

As survivor advocates and co-researchers the WEAVERs work in a variety of ways aligned with the *Principles of the Family Violence Experts by Experience Framework* (co-produced by the WEAVERs in 2020). At the time that framework was being developed the WEAVERs group included two lived experience researchers and eighteen victim survivor co-researchers.

More information about the WEAVERs is available at <u>www.saferfamilies.org.au/weavers</u>. The Family Violence Experts by Experience Framework is available at <u>safeandequal.org.au/working-in-family-violence/service-responses/experts-by-experience-framework</u>

Terminology

The use of language is an important one in the domestic, family and sexual violence fields (Easteal, Bartels, & Bradford, 2012) and clarity of communication is a key component of effective co-design (Faulkner & Thompson, 2021). Therefore it is important to outline the terminology that is used throughout this Framework (see Table 1).

Table 1: Terminolo	ogy used in the Framework
Research	Inclusive of qualitative, quantitative research and evaluations.
Lived experience	A person who has experienced any form of domestic, family, intimate partner or sexual violence as a child or an adult and brings their 'expertise by experience' to their work.
Co-produced research	 Comprises both co-designed and co-created research. Co-designed research engages people with lived experience (victim survivor co-researchers and lived experience researchers) in research or evaluation after the research questions has been determined or the funding received. People with lived experience are then involved in <i>all stages</i> of the research project from research development to dissemination. Co-created research has the same elements of co-designed research but people with lived experience <i>are also</i> involved in setting the research agenda, selection of the topic to research and the approach taken.

Researchers

It is important to note that the categories of researchers are not hierarchical. The Framework supports the development of research teams that are made up of researchers from diverse backgrounds and with varied experiences and both academic expertise and expertise by experience with power and decision-making shared across the group.



Table 1 (continued) : Terminology used in the Framework
Academic researcher	A person who has research qualifications and who is employed in their role due to these qualifications. They may be employed in any setting including a university or other training body, government, or private sector. Many academic researchers have lived experience of domestic, family or sexual violence and bring a lived experience lens to their research work. Sometimes researchers are specifically employed as 'lived experience researchers' while other academic researchers may or may not choose to disclose their lived experience.
Victim survivor co-researcher	Someone with lived experience of domestic, family and sexual violence who works as a co-researcher alongside academic researchers and/or lived experience researchers.
Victim survivor advocate	Someone with lived experience of domestic, family and sexual violence who provides advisory or collaborative support to a research project.

About co-produced research and evaluation

There has been a shift over time in a range of community health and social services towards research approaches that are more collaborative, inclusive and democratic (Oliver, Kothari, & Mays, 2019). Literature from the United Kingdom shows considerable progress in the engagement of people with lived experience as research partners in co-production processes (King & Gillard, 2018). This shift has led to the development of a range of research approaches which are described as participatory, co-produced or co-designed. The momentum of uptake of this type of research approach has been greatest across the mental health (King & Gillard, 2018); broader health care sectors (King & Gillard, 2018; Oliver et al., 2019) and with Indigenous populations internationally (Baum & Simpson, 2006; Jull, Morton-Ninomiya, Compton, & Picard, 2018).

It is difficult to obtain consistent or universal definitions of 'participatory research', 'co-designed' or 'coproduced' research (Oliver et al., 2019; Thomas-Hughes, 2018). However it is agreed that these approaches challenge 'traditional power dynamics by valuing the expertise of experience' (Darby, 2017, p. 231). Throughout the literature, co-production is generally acknowledged as occurring across a continuum; ranging from relatively low levels of engagement where people with lived experience have limited involvement or degree of influence over the project, to work that is initiated and led by people with lived experience (Werner-Seidler & Shaw, 2019). Definitions of co-produced research often describe involvement of people with lived experience in the research or evaluation from conceptualisation and design; collection and analysis of data and dissemination of research findings (Redman, Greenhalgh, Adedokun, Staniszewska, & Denegri, 2021).

This participatory approach fits particularly well with a feminist research approach which underpins much

research in the domestic, family and sexual violence sectors (Johnson & Flynn, 2021). Early responses to intimate partner violence were driven by activists in partnership with women with personal experience of violence (Hague & Mullender, 2006; Theobald, 2009). Feminist researchers view victim survivors as having valuable knowledge and expertise about the violence. This view has gained traction in recent years with efforts focussed on exploration of ways to ensure victim survivors are centred as 'legitimate sources of knowledge' in research and evaluations about intimate partner and sexual violence (Campbell & Wasco, 2000, p. 773).

"Well, I think, speaking for myself, it gives women such as myself, who's never had a voice, a chance to have a voice, and also women in our position - I was in my relationship for 29 years, so I have a lot of experience in that. It finally gave us a chance to say look this is what we think is important". (WEAVER member)

Development of the Framework

In 2020 the University of Melbourne Safer Families Centre team and WEAVERs co-produced a framework to support specialist family violence services engage victim survivor advocates in the development of policies, programs and practice with support from the peak body for specialist family violence services, Safe and Equal, formerly Domestic Violence Victoria. The Family Violence Experts by Experience Framework was primarily designed for use within Victoria, Australia but has also been utilised nationally.

Two years later, the World Health Organisation (WHO) and University of Melbourne agreed that a similar framework was needed to support collaborative or co-produced *research and evaluations* about domestic, family or sexual violence with victim survivors in an international context. Both organisations provided funding for this work to proceed. The Australian Framework will be used by the WHO as the basis for consultation with victim survivor groups in other countries to develop a global framework.

As part of the Framework's development, an extensive scoping review (see Appendix 1 for a full description of the literature review findings) was conducted to identify frameworks, best practice or ethical guidelines focussing on providing guidance for undertaking co-produced research with victim survivors of domestic, family and sexual violence.

While seven documents were found which provide useful context, only two directly relevant frameworks were found:

- Goodman et al. (2017) Power through Partnerships: A CBPR toolkit for domestic violence researchers. National Resource Centre on Domestic Violence, Harrisburg, PA. Retrieved from <u>https://cbprtoolkit.org/</u>
- Perot, C., Chevous, J., & Survivors_Voices_Research_Group. (2018). Turning Pain into Power: A Charter for Organisations Engaging Abuse Survivors in Projects, Research & Service Development Retrieved from <u>https://survivorsvoices.org/charter/</u>

Both these frameworks (as well as the five supporting documents) have heavily informed the development of the principles for the current Framework.

The Framework comprises three parts:

- Part A: Continuum of participation of victim survivors
- Part B: Best practice principles for ethical co-production
- Part C: Resources and tools for academic researchers and victim survivor co-researchers

Part A: Continuum of participation of victim survivors

"Listening to others share their experiences which are similar to mine doesn't make me alone in it. Yeah, and that there is a kind of universal dimension to what I have experienced. There's a sense of - you know, a reaching out to the others. Within me there is a reaching out to the others and perhaps that's reciprocal. Maybe they're reaching out to me too. It's only if you've experienced it can you, I suppose, deeply understand that experience". (WEAVER member)

Continuum of participation: from research participant to partners in co-production

It was felt that it was important to have a clear model defining co-production within this Framework to ensure that activities which were really consultative rather than true co-production were not mislabelled (McKercher, 2020). As mentioned earlier, no existing continuums fully resonated with the victim survivor co-researchers or research team and so a continuum was developed, building upon existing continuums of participation (Hart, 1992; The Home Visiting Applied Research Collaborative, 2018; Vargas, Whelan, Brimblecombe, & Allender, 2022).

The development of this continuum was much harder to articulate than was anticipated and was (perhaps fittingly) a significant piece of co-produced work in itself. The Framework model may require future refinement following broader dissemination and discussion. The continuum ranges from victim survivors being research participants; through to partners in co-creation. It is not designed to preference one approach over another. It is designed to support clear decision-making and explanation of the approach adopted and how it fits with other methods as well as an attempt to define the key elements of co-production.

The Framework continuum divides research that involves co-production into two categories:

Co-design- where the research topic is determined by researchers, funders or other entities and then victim survivor co-researchers are invited to express interest in becoming involved. All aspects of the research process are then carried out in partnership with victim survivors and researchers using co-production processes.

Co-create- research projects adopting this approach engage victim survivors and researchers in processes to decide and determine the area of focus for the research and then work in partnership to complete all aspects of the research process through to dissemination.

It is important to note that while decisions about the degree of engagement of victim survivors in the research process may be open and flexible for some projects, in others, they may be constrained by external factors (for example, budget; timelines; the source of funding; funder requirements and ethics processes). What is key, is that the project approach is transparent and clearly documents where it sits on the continuum and why.

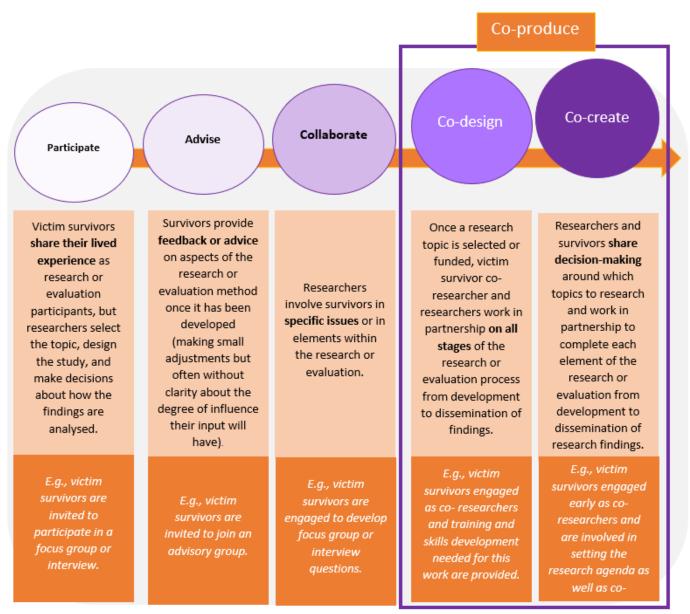


Figure 1:

Continuum of participation of victim survivors in research about intimate partner and sexual violence.

See Resource 7 for examples of research projects which sit at each of these levels of participation.

Part B: Best Practice principles for ethical co-production

"I have fought really hard to not continuously have identities imposed onto me by more privileged people, of them seeing me as being vulnerable, of being victim, of being a 'lost cause' and this was another thing, identity invasion, or having my identity written off, that motivated me to join this panel as it is empowering to be in a space where you are respected for your experiences and respected for who you are in a mutually supportive peer space". (WEAVER member)

Best practice principles for co-produced research with victim survivors

Members of the WEAVERs lived experience group were instrumental in drafting key best practice principles to guide the ethical engagement of victim survivors of domestic, family and sexual violence in collaborative or co-produced research (with input from the Safer Families Centre team). The table below outlines the key principles as well as potential strategies to put these principles into practice.

Principle	Description	How to put this principle into practice
Agency	Victim survivor co-researchers are provided with the information and support they need to make informed choices and decisions about their participation and boundaries.	 Emphasis should be on empowering victim survivors to self-reflect and make their own decisions about participation in a research project and supported to establish boundaries around their engagement.
Transparency	The research process, level of involvement, opportunities to review and dissemination plan are clearly communicated to victim survivor co-researchers.	 Recruitment processes should clearly outline the parameters of partnering, remuneration and what is required. The potential reach and degree of influence of the research should be realistic and clearly explained.
Healing informed ¹	The research process is developed with an understanding of the impacts of trauma but is shifted to focus on facilitating healing (through empowerment, enhancing agency) rather than focused on preventing distress.	 The research process should be designed in a way that enhances healing rather than addresses potential harm. While safety is an important principle there should also be a focus on how the co-production research process can support empowerment, build confidence and social connectivity, and enhance skills of the victim survivors.

Table 2: Principles for co-produced research with victim survivors

¹ The term 'healing informed' rather than the more commonly used 'trauma informed' has been used due to the WEAVERs preference for this term and its positive strengths focus and consistency with the concepts of empowerment woven throughout this Framework. It is a term that has been used in the literature with reference to indigenous populations within Australia and internationally and also in relation to youth engagement (Ginwright, 2018; Hastie-Mendoza, Tinajero, Cervantes, Rodriguez, & Serrata, 2018)

Safety & Support ²	Victim survivor co-researchers are empowered to prepare themselves for participation and to pre-empt potential impacts and the supports they might need for safe and effective collaboration.	 Ensuring that victim-survivors complete self-reflection questions and using that as a guide to see how the project could be tailored to enhance safety (if no supports are identified, consider and outline what other supports that the individual could access that are trauma informed and easy to access). Always have at least two people with lived experience working on a project and an equal number of people with lived experience and academic researchers to support reduction of power imbalances.
Researcher preparedness	Researchers are appropriately trained and prepared to work with victim survivor co- researchers in a non- judgemental healing informed way and have the supports they need if they hear about distressing experiences and events.	 Processes are in place to ensure all members of the research team have an understanding of trauma/healing informed practice. All researchers are provided with guidance around the importance of self-care and the impact of vicarious trauma (including ensuring support services are available for researchers through Employee Assistance Programs or other means).
Mutual exchange	Engagement with victim survivor co-researchers promotes mutuality where everyone is learning and sharing knowledge and where everyone on the team's opinion is heard and decision-making shared.	 Create an environment where it is recognised that each member of the co-production team brings expertise in their own right.
Recognise and Value	The unique expertise and contributions of victim survivor co-researchers is explicitly acknowledged and highlighted in the research process and reporting. Everyone should be compensated for the time they put into the research and their costs to participate, to show respect and acknowledge that their contribution is valued.	 It is a fundamental principle of ethical co- produced research in the IPV and SV sector that all members of the team should be renumerated (via cash, paid positions of employment or vouchers and that this should be clearly explained prior to the project commencing). Ensure opportunities to publish articles and report, speak at conferences, meetings, webinars, other means of dissemination of outcomes are shared and co-led.
Comfort with discomfort	The environment should support all collaborators feeling they can be honest, with adequate time set aside for reflection and feedback about the things that are working well and the things that are not.	 It is important that the challenges of co- produced research processes are acknowledged and that everyone on the team agrees to be willing to embrace different perspectives and ways of working.

² Safety is considered inclusive of physical, emotional, legal, spiritual and cultural safety (Hegarty, Andrews, & Tarzia, 2022).

Relationships	Build honest and trusting relationships where power imbalances are identified and efforts taken to address them.	Establish an environment where everyou comfortable sharing their motivation for engagement (linked to transparency). Acknowledging that there may be difference reasons to engage. Clear communication how the experience views shared will be applied.	r ent
Inclusion	In order to gain insight from a broad range of perspectives, a diverse range of survivor voices (e.g. those with a disability, chronic illness, mental illness, culturally diverse, LGBTIQ+, diverse identities, circumstances and ages) should be sought for inclusion in the research collaboration. Where this cannot be achieved it should be explicitly noted.	Develop a skills and experience matrix. Make participation accessible (different may have different accessibility requirer so, check in and gain access to supports individuals identify they need to particip	nents; that
Individualised and flexible	Research processes are flexible enough to ensure that a variety of preferences and styles of working are accommodated as well as support inability to engage on some days. Support and development opportunities are provided that are suited to the individual needs and interests identified by victim survivor co-researchers.	The inclusion of more than one lived exp co-researcher on each project to allow for flexibility and potential for anyone who time out from a project to do so. Seek to understand where each team m interests and aspirations lie and actively opportunities for skill development in lin these.	or needs embers look for
Accountability	Co-produced work with survivors is subject to regular review, evaluation, debriefing and accompanied by clear complaints and feedback mechanisms.	Establishment of processes to gather fee about how the co-produced research pro- being experienced by all parties through life cycle of the project. This information then be used to fine tune and modify we practices for the next piece of co-produc research.	ocess is out the can ork
Differences in opinion	All discussions will occur in a respectful way and differences of opinion will be talked through to attempt to reach agreement. Processes for the resolution of more challenging issues should be outlined and discussed at the project commencement.	Development and early articulation of cl processes for how decisions will be mad throughout the research particularly wh researchers and victim survivor co-resea disagree.	e en the

Part C: Resources and tools for academic researchers and victim survivor coresearchers

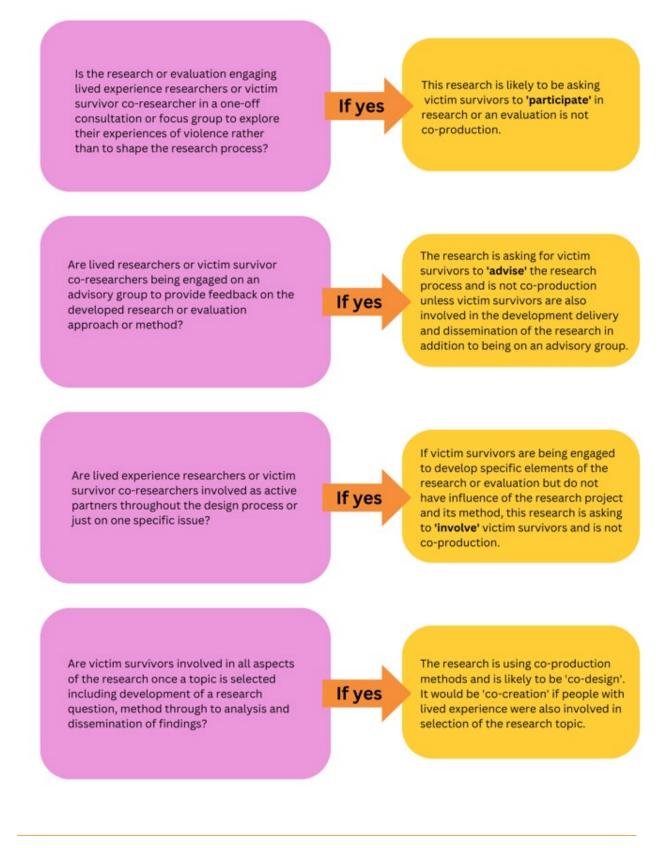
The WEAVERs and Safer Families Centre team agreed that examples were needed about how these principles might be put into practice within the context of a research project. As a result, resources and tools were co-produced. These resources include:

- Deciding whether the research is co-production (Resource 1)
- Self-reflection questions-for people with lived experience (Resource 2)
- Self-reflection questions- academic or lived experience researchers (Resource 3)
- Research Project commencement prompts (Resource 4)
- Evaluation questions (Resource 5)
- Human Research Ethics Considerations (Resource 6)
- Research project examples showing each level of participation on the continuum (Resource 7)

"I also wanted to join this panel because there are many issues I have lived and see other women living and experiencing in my families and communities that have not been addressed by research or by previous royal commissions or inquiries, or even by this recent royal commission, and it is important to ensure these issues and voices and proposed solutions to issues are heard to create change that includes peoples who are most disadvantaged by the system or excluded from the system or who fall through the gaps of the system for various reasons". (WEAVER member)

Resource 1: Is this project co-production?

As outlined in the Framework, there are no agreed definitions of collaboration, co-design or co-production but a number of authors (McKercher, 2020; NCOSS, 2017; Slattery, Saeri, & Bragge, 2020) have outlined some key questions to consider when determining whether a project or research is being co-produced. Our reflections build on those questions but also on our own continuum.



These questions are designed to support people with lived experience reflect and make a decision about whether to partner on a co-produced research project. The questions have been developed with reference to the 'self-reflection questions' for victim survivors in the *Family Violence Experts by Experience Framework (2020)*.

Readiness to undertake the work

- What are my reasons for wanting to become a co-researcher on this project?
- Do I really want to become involved or am I feeling that I should?

Resources needed

- Do I have enough resources in place both personally and professionally to prevent my health and wellbeing being negatively impacted?
- What support might I need if my health and wellbeing is negatively impacted?
- What strategies will I use if someone (could be a research participant I am interviewing for example) reacts negatively or judgmentally?

Safety considerations

- Is it safe for me to become involved?
- Are there any ongoing risks posed by the person/s who abused me?
- Are there protections that can be put in place to increase my safety?

Boundaries

- How will I ensure my personal and professional boundaries are upheld?
- What are my personal limits regarding what I am happy to contribute?

Legal considerations

- Am I involved in any ongoing legal proceedings that may be jeopardised?
- Are there any potential legal consequences for me becoming a co-researcher on this project?

Other considerations

- Are there people in my life who need to be aware of my decision to become a coresearcher on this project?
- Am I clear about how I would make complaints or provide feedback?

These questions have been designed to generate thought and discussion for researchers considering engaging in co-produced research with victim survivors of domestic, family and sexual violence:

- Does the research project have the resources, funding and timelines to support a meaningful and ethical co-produced process with victim survivor co-researchers?
- Am I familiar with the best practice principles for engaging in co-production with victim survivors? Am I comfortable that I know how to put these principles into practice in my research work?
- Do I have a strong understanding of healing and trauma informed approaches, and do I know how to apply these principles in the context of a research project, if not can I access training or other opportunities to build my capacity?
- Have I got access to emotional support and guidance if challenges arise in the project, or I become distressed?
- Do I have existing networks or connections to victim survivors with research experience? If not, can I establish a group and support them to develop relevant research skills within the timeframes of the project?
- Am I comfortable working in a non-hierarchical project structure where I will be sharing power and decision-making with victim survivor co-researchers? Have I reflected on what changes I might need to make to the way I work?
- Am I trained and able to provide first line emotional support and referrals to victim survivor co-researchers if its needed, or are there others in my team or can I partner with an organisation who can?
- Is it possible that this research will touch on some areas where I have lived experience? Have I thought about whether I will disclose this experience or not? Where can I get support if I need it?
- Are there any additional skills I might need to develop before I engage in co-produced research?

Resource 4: Project commencement prompts

This document has been designed to support the commencement of co-produced research projects which involve lived experience researcher and/or victim survivor co-researchers ³.

Suggested steps	Resources
Before project commences	Resources
Determine whether the research project is a genuine co-production process and ensure	
all members of the research team have a shared understanding of what co-production is.	Resource 1
Complete a Human Research ethics application outlining how the research project will	Best practice
adhere to and apply the ethical co-design framework principles.	principles
	Resource 6
Distribute self-reflection questions to all project team members and ask whether any issues emerged.	Resource 2
Discuss these issues with the group and note that anyone is welcome to share their thoughts with the group or have a private conversation with the project manager if they prefer.	Resource 3
Confirm in writing how each victim survivor co-researcher would like to be	
remunerated/paid for their participation in this research (e.g., casual contract, or	
honorariums such as vouchers).	
At first project meeting	
Introduce with an activity designed to increase connection and relationships and an	
understanding of everybody's motivation, priorities, and interests.	
Discuss clearly at the first meeting:	
The role everyone will play in the project	
Decision-making processes	
Conflict resolution processes	
Plans for publications and authorships	
Explain in detail the potential degree of influence of the work (what outcomes are	
possible and what are unlikely). Ensure that everyone has realistic expectations about what change the work might influence.	
Ensure everyone is clear about the process for raising any concerns or complaints during	
the project and what they can expect to be done if a complaint is raised.	
Early in the project make time for team discussion using the following questions based	
on the best practice principles:	
Healing informed- What opportunities are there for our approach to this research to contribute to healing?	
Safety- How can we make sure that everyone feels safe when working together on this research project?	
Mutuality - How can we approach this work in a way that ensures everyone on the	
team's opinion is heard and decision-making is shared given different positions of	
power?	
Inclusion- Whose voice will not be heard in this project and how will this be	
acknowledged?	
Review the co-production process and experience at key points throughout and at the conclusion of the project	
How did co-production project team members find the research process and what	
outcomes were achieved as a result of this process?	Resource 5

³ Shimm, C., Wittmeier, K et al. (2017), 'Moving towards a more inclusive patient and public involvement in health research paradigm: the incorporation of a trauma informed intersectional analysis', *BMC Health Services Research*, 17: 539 (adapted from)

It is important project members of the co-production team take the time to reflect on the research process and outcomes.

Key questions that might be considered:

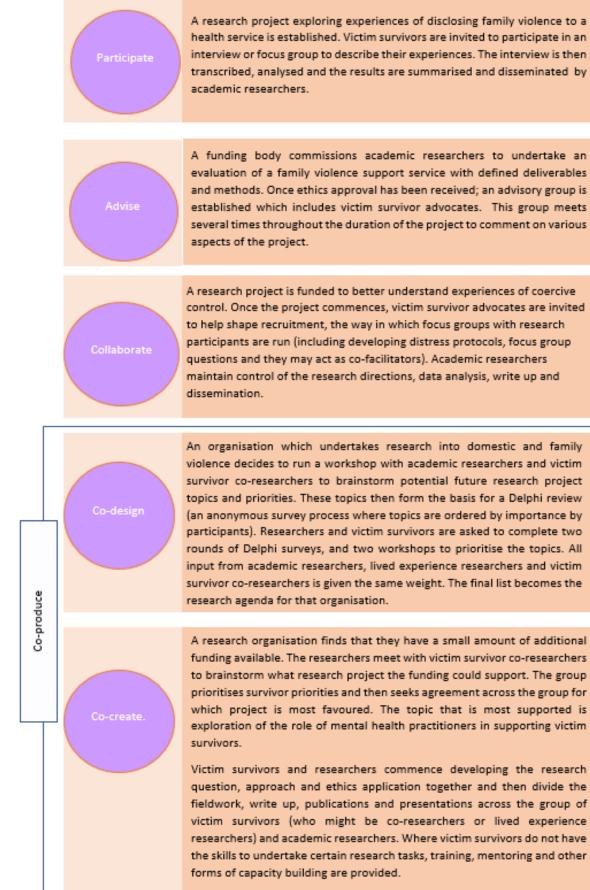
- How well were the co-production principles implemented in practice?
- How listened to and respected did each of the research team members feel?
- Did the co-production process create benefits (for the research outcomes or for individuals in the team)?
- Did the co-production process create challenges?
- Were there any key enablers that were important to support this work?

Resource 6: Human research ethics applications considerations

The following list of questions are provided as prompts for anyone preparing or assessing a Human Research Ethics Application for a research project which involves elements of co-design with victim survivors of domestic, family intimate and sexual violence. We note that some of the issues raised here might be beyond the scope of the formal Human Research Ethics process, but we think they are important context to think about and consider when preparing an application.

- Are the research timelines and resources adequate to allow for genuine coproduced research?
- Are there adequate opportunities for victim survivor co-researchers to shape the design and direction of the research in meaningful ways?
- How will victim survivor co-researchers be recruited?
- How will victim survivor co-researchers be paid for their time and is the rate of pay adequate?
- What processes will be put in place to facilitate the participation of victim survivor co-researchers while also enhancing safety?
- How are victim survivor co-researchers being supported to assess their own readiness to participate in the research?
- What processes are in place to ensure a diverse range of victim survivor voices are sought?
- What supports (including emotional, logistical, technical or peer support) will be provided to victim survivor co-researchers and by whom?
- How will the project support victim survivor co-researchers build and extend their skills and capacity?

Resource 7: Research project examples showing each level of participation on the continuum



Areas for future exploration

This Framework has been developed to help support organisations and researchers who are interested in coproducing research with victim survivors of intimate partner and sexual violence. It has been designed to provide some best practice principles, guidance and tools to support that work based on the University of Melbourne and WEAVERs experiences of undertaking this work together over the past six years. However, the most important role of this Framework is to start more conversations about co-design research so it can be demystified, enhanced through institutional change and more widely adopted. There are still a number of areas where further discussion and consideration is needed and some of these are briefly outlined below.

Co-produced research cannot be conducted in a vacuum, it needs to be supported by structural and institutional conditions which facilitate research of this type.

It has been well documented that co-production is only possible in organisations where the culture supports a shift in power where people with lived experience become active partners rather than passive recipients (Burkett, 2012). In addition to cultural support, some of the traditional models of applying for and receiving research funding and can place barriers in the way of ethical co-produced research processes (Gaffy, Brijnath, & Dow, 2022). For example, some processes require grant applicants to apply to conduct research on predetermined topics, or fully developed research methods prior to applying for funding and engagement of coresearchers. It also needs to be acknowledged that additional time and resources will always be needed to facilitate meaningful and ethical co-produced research.

One of the key elements of successful co-produced research is that relationships and capacity are built and strengthened over time.

In order for effective co-production to occur, trusting relationships need to be built and participants require access to the information skills and support to be able to participate fully (Burkett, 2012). At present in the domestic, family and sexual violence sectors there is often not adequate funding for sustained engagement and development of co-researchers. While the inclusion of requirements to engage victim survivors as experts by experience in research projects is important, this needs to be supported by investment in training, education and support. This would allow a variety of victim survivors with diverse experiences and perspectives to be included and also allow for the relationships between researchers and victim survivor co-researchers to be sustained longer term.

Human Research ethics processes currently do not support or provide much assistance to researchers wanting guidance around co-produced research.

Existing Human Research Ethics protocols were primarily developed in the biomedical sciences to support the ethical conduct of scientific research conducted through random controlled trials. They are less well suited to qualitative research. It has been suggested that Human Research Ethics protocols sit even more 'oddly' when considering co-produced research which is of highest ethical quality when the research method is flexible, where power is shared and where there is just as much focus on potential for impact and empowerment as prevention of harm (Goodyear-Smith, Jackson, Greenhalgh, & Brooks, 2015). This tension is one that has received some attention in the literature but has not led to widescale reform within academic and government research institutions and is another area identified for further discussion.

Greater understanding is needed of the impact of co-production methods

While there is increasing recognition of the value of adopting co-production research methods in a range of policy areas (including health and mental health) less is known about the impacts and outcomes achieved and how the process is experienced by researchers and victim survivors. This limits knowledge-sharing and evidence building (Blomkamp, 2018). Further discussion is needed to explore how co-production processes are monitored, refined and improvements made as well as calculations about the resources required to effectively support this work.

What best practice frameworks exist for conducting co-produced research into intimate partner and sexual violence with victim survivors?

Introduction

Increasingly consumers are being engaged in policy and service design across a range of health and community services sectors in recognition of the potential benefits both for service efficacy and the individuals themselves (Ghanbarpour, Palotai, Kim, Aguilar, Flores, Hodson, Holcomb, Jimenez, Kaur, Pusey, Rosales, Schlater, & Shim, 2018; Werner-Seidler & Shaw, 2019). This shift has occurred as part of a wider move towards participatory practices in areas such as the arts, industry, and government (Facer and Enright, 2016).

In parallel, there has been growing international interest in the exploration of research approaches that promote the autonomy and voices of marginalised groups (Aldridge, 2015). Some researchers have been looking for ways to situate individuals and communities as partners rather than as research subjects (Howard & Thomas-Hughes, 2021, p. 788; Lake & Wendland, 2018). This has led to the development of a range of research approaches which are described as participatory, co-produced or co-designed. The momentum of uptake of this type of research approach has been greatest across the mental health and broader health care sectors internationally (King & Gillard, 2018; Oliver et al., 2019).

It is difficult to obtain consistently agreed definitions of 'participatory research', 'co-designed' or 'coproduced' research (Oliver et al., 2019; Thomas-Hughes, 2018). However it is agreed that these approaches challenge 'traditional power dynamics by valuing the expertise of experience' (Darby, 2017, p. 231). It is also agreed that co-produced research is not a unique research method in itself, but rather an approach that frames knowledge production as a process relying on interaction between researchers and others concerned with what is studied (Darby, 2017). However it is generally agreed that co-production occurs across a continuum ranging from relatively low levels of engagement, to work that is led by people with lived experience (Werner-Seidler & Shaw, 2019).

Co-produced research has been acknowledged as ethically messy and complex work (Beckett, Farr, Kothari, Wye, & le May, 2018). Traditional human research ethics approaches often do not fit well with co-produced research and often fail to provide practical guidance for researchers. In order to determine what guidance exists to support domestic, family and sexual violence researchers and where the current gaps lie a literature was undertaken.

The research question guiding the literature review was:

What best practice frameworks exist for conducting co-produced research into domestic, family and sexual violence partner and sexual violence with victim survivors?

The findings of this literature review will underpin the development of a framework and tools to provide ethical principles and practical examples to guide co-produced research with victim survivors internationally.

Scoping Review Method

Search Strategy

An initial search of articles published between 2016 to 2021 was conducted in December 2021 using seven electronic databases. The databases search used combinations of the following terms: 'coproduced', 'co-production', 'co-design', 'consumer-led', 'co-construction', 'co-creation' AND 'lived experience', 'expert by experience', 'consumer*', 'service users' AND 'domestic violence', 'domestic abuse', 'family violence', 'intimate partner violence', 'intimate partner abuse', 'battered women', 'spouse abuse', 'violence against women', 'sexual abuse', 'sexual assault', 'sexual violence' AND 'research frameworks' 'research guidelines', 'best practice research'.

We were looking for frameworks which give guidance to domestic, family and sexual violence researchers who want to co-produce research with survivors/people with lived experience. We searched the following databases: OVID Medline and OVID PsycINFO, CINAHL, ASSIA, Embase, SocIndex, and Cochrane library. The initial database search revealed 1,066 articles. Of these, 15 were duplicate studies and were removed prior to screening titles. The Screening process found seven relevant papers with two frameworks identified for the review.

Review Context

Evidence suggests that women who experience domestic, family and/or sexual violence often describe feeling silenced not only by the person using violence but also the service system and society more broadly (Hague et al., 2003). This can further contribute to women's feelings of disempowerment, isolation and fear (Dobash & Dobash, 1992). Capturing the stories, experiences, and voices of victim survivors through research has been seen as a positive way of potentially addressing this imbalance and increasing societal awareness.

The engagement of victim survivors in research has occurred across many disciplines and using a variety of approaches (World Health Organization, 2016). However not all of the research has been experienced positively by survivors and services. Some research has been described as 'extractive' where information is harvested from survivors (particularly in marginalised groups or communities) who never hear how this information was used and what the outcomes of its use were (Ghanbarpour et al., 2018, p. 527; Goodman, Thomas, Serrata, Lippy, Nnawulezi, Ghanbarpour, Macy, Sullivan, & Bair- Merritt, 2017).

These concerns have led to the development of several frameworks internationally which provide ethical guidelines and advice for researchers engaging with victim survivors as participants of research (Ellsberg & Potts, 2018; Women's_Aid, 2020; World Health Organization, 2001, 2016). These frameworks identify some common key principles for ethical research with participants including:

- Protecting the safety and privacy of participants
- Being transparent about what the research requires and potential influence
- Being mindful of power imbalances
- Ensuring researchers are trained and supported
- Building in distress management approaches and referral pathways
- Inclusion of diverse survivor voices and perspectives
- Ethical dissemination and contextualisation of research findings

There has also been a broader shift across health and community service towards an approach to research that is more collaborative, inclusive and democratic (Oliver et al., 2019). Literature from the United Kingdom shows considerable progress in the engagement of people with lived experience as research partners in coproduction process (King & Gillard, 2018). This approach fits with a feminist research framework underpinning the domestic violence sector where early responses to domestic violence were driven by activists in partnership with women with personal experience of violence (Hague & Mullender, 2006; Theobald, 2009). Feminist researchers viewed victim survivors as having valuable knowledge and expertise about domestic violence, this view has gained traction in recent years with efforts focussed on exploration of ways to ensure victim survivors are centred as 'legitimate sources of knowledge' in research about intimate partner and sexual violence (Campbell & Wasco, 2000, p. 773). The importance of ensuring victim survivors voices are present in research design is directly called out in some research frameworks (Women's_Aid, 2020).

This is consistent with the broader movement towards involving victim survivors in the development of service and policy responses to domestic abuse and violence in recognition of their expertise by experience (Hague & Mullender, 2006). This is a key point echoed in the *Family Violence Experts by Experience Framework* developed in 2020 by the University of Melbourne researchers and lived experience WEAVERs group for the peak body, Domestic Violence Victoria (know known and Safe and Equal). (Lamb, Hegarty, Amanda, Cina, Fiona, & Parker, 2020). Many of the best practice principles of this framework echo the principles highlighted in earlier research frameworks and summarised above, including the importance of support, safety, and transparency. While not focussed on research specifically, the *Experts by Experience Framework* does outline additional best practice principles that are important to facilitate ethical co-production in the context of the development of services and policies in the domestic violence sector. These additional principles include:

Recognition: Victim survivors are acknowledged as holding valuable knowledge and expertise which is reflected in organisational policies and governance structures.

Value: In addition to being provided with recognition for their expertise, survivor advocates will be financially remunerated for their time, contributions, and expenses when they provide significant input into policy and practice.

Accountability: Engagement with survivor advocates is subject to regular review, evaluation and accompanied by clear complaints and feedback mechanisms.

Trust: Relationships between services and survivor advocates will be collaborative and built on trust. Power imbalances are addressed by reducing traditional barriers and by genuinely involving survivor advocates in decision-making.

Reciprocity: Engagement with survivor advocates will promote mutuality and will be governed by shared information exchange and learning.

Sustainability: Formal engagement with survivor advocates is adequately resourced to allow longer term work, for partnerships to be built and key learnings to be shared.

Existing Frameworks for conducting codesigned research with victim survivors of domestic violence

As outlined in the method section, an extensive scoping review was conducted to identify any frameworks, best practice or ethical guidelines which specifically focussed on providing guidance for undertaking coproduced research with victim survivors of domestic, family and sexual violence. While seven documents were found which provide useful context, only two frameworks were found, and these were:

- Goodman et al. (2017) Power through Partnerships: A CBPR toolkit for domestic violence researchers. National Resource Centre on Domestic Violence, Harrisburg, PA. Retrieved from <u>https://cbprtoolkit.org/</u>
- Perot, C., Chevous, J., & Survivors_Voices_Research_Group. (2018). *Turning Pain into Power: A Charter for Organisations Engaging Abuse Survivors in Projects, Research & Service Development* Retrieved from <u>https://survivorsvoices.org/charter/</u>

Framework One: Power through Partnerships Community Based Participation Research Toolkit (United States)

The Power through Partnerships is a Community Based Participation Research (CBPR) Toolkit which was developed to support researchers interested in adopting CBPR approaches to work in partnership with those impacted by intimate partner and sexual violence and the services who support them. Specifically, the toolkit was designed to support domestic violence researchers, ' share power, resources, and decision-making at every level of the research process' (Goodman et al., 2017). It is important to note that the framework supports researchers wanting to undertake co-production with both victim survivors and community organisations.

The CBPR approach to domestic violence research aims to answer four key questions:

- What are the critical questions for survivors and practitioners in this community?
- How can we best explore such questions using strategies that are clear, consistent, and replicable; that is, scientifically rigorous?
- How can we ensure that these strategies are sensitive to the backgrounds, cultural practices, and life contexts of community stakeholders?
- How can we interpret and disseminate our findings in ways that benefit survivors, practitioners, and communities?

The CBPR toolkit focuses on the importance of considering trauma experiences of survivors and potentially staff working in community organisations. The toolkit also notes the importance of ensuring methods and strategies are flexible and can be adapted if unpredicted issues arise. The toolkit also notes the importance of keeping timelines realistic and adequate to allow everyone to review and provide feedback as the projects progresses.

The toolkit also recommends that researchers engage in self-reflection before they commence co-produced research with victim survivors and/or community organisations:

If you do not understand yourself as an instrument in this work, you will fundamentally misunderstand your own actions and reactions, as well as those of others. Self-knowledge and reflection will help you to minimize the risk of unintentionally introducing bias into your research projects or tensions in your relationships. (Goodman et al., 2017).

Like the other frameworks for ethical domestic violence research, the toolkit for CBPR emphasises the importance of considering power imbalances (Lamb et al., 2020; Perot, Chevous, & Survivors Voices Research Group, 2018). The toolkit notes that as coercion and control lie at the heart of domestic violence, victim survivors are often 'highly attuned' to the dynamics of power within relationships including between themselves and researchers (p.44).

The importance of considering structural inequalities when conducting violence about intimate partner and sexual violence has been noted (Women's_Aid, 2020) and the CBPR Framework provides some key questions for researchers to consider how power imbalances might be operating in the research project between researchers, community organisations and individuals:

- How is structural oppression functioning through the project?
- How can this project increase the equitable distribution of resources?
- How are you building access for marginalised communities?

Another way that power imbalances can manifest in research projects is in the way decisions are made. The toolkit places emphasis on ensuring that decision-making is shared by professionals and victim survivors across

different stages of the research from early planning through to dissemination and that this is a structured agreed process:

Ideally, discussions about decision-making processes should be formalized through an organized, coherent, and collaboratively developed plan that is documented and shared by those involved.(Goodman et al., 2017)

Finally the toolkit notes that the research findings should be owned by all researchers, survivors and community organisations involved and decisions about how to diseseminate the findings should be made together and formally doccumented. It is reocmmended that the focus of dissemination is to look for ways that those who are most inpacted by the issue being studied should be able to access the findings easily with an emphasis on ensuring information is presented in a way that busy practitioners can acess.

Framework Two: Turning Pain into Power: A Charter for Organisations Engaging Abuse Survivors in Projects, Research & Service Development (United Kingdom).

The second framework identified was the *Turning Pain into Power Charter (Perot et al., 2018)*. This Charter was developed in the UK by a partnership of survivor activists. The Charter aims to provide good practice guidelines for organisations, services and researchers who want 'active, safe and meaningful' engagement with victim survivors.

The key tenet of the charter is that 'all work with people affected by abuse and trauma needs to look unlike and be the opposite of abuse'(p.2). Like the frameworks previously listed, the Charter notes the importance of ensuring survivor engagement is safe, with safety defined broadly as including ensuring a safe engagement environment, with dedicated time to build trust.

Consistent with other *Frameworks (Lamb et al., 2020; Women's_Aid, 2020)*, the Charter emphasised the impotrance of ensuring that safety concerns are not used as a means for exclusion and the importance of victim survivors playing a pivotal role in deciding whether participation would be harmful or not and how they will manage distress:

We will acknowledge that individual and organisational fears about the risks of 'opening Pandora's Box' can silence survivors and prevent meaningful dialogue, engagement, and partnership with survivors. Enabling dialogue about abuse may cause distress, however, distress does not automatically lead to damage. Instead of avoiding the subject of abuse, we will learn to ask well, work collaboratively and give choice in a safe and supportive atmosphere (Perot et al., 2018).

In addition, the Charter calls for recognition that when survivors experience distress this should not be 'pathologised' but seen as natural part of the work. The charter calls for support to be offered to survivors to enable them '..to be real about struggles and 'not-ok' days and ensuring sufficient 'back-up'. (Perot et al., 2018).

Consistent with other frameworks (Lamb et al., 2020) the Charter underscores the importance of ensuring that research engagement with survivors has clear communication and accountability as well as feedback and complaints processes:

Abuse is hidden, and abusers often act with impunity. Engagement with survivors must have clear lines of communication and accountability, including to survivor-participants and survivor communities. Processes and decision-making should be relational, honest, real, transparent and open to feedback and dialogue (Perot et al., 2018).

The importance for co-produced work with victim survivors to be trauma informed is emphasised by a number of frameworks (Goodman et al., 2017; Lamb et al., 2020; Women's_Aid, 2020) including the Charter with examples given about how a trauma informed approach might be adopted in practice:

We will offer deep listening, empathy and non-judgemental acceptance, acknowledging our intent to be helpful and actively inviting survivors to voice anything that feels uncomfortable or triggering. To support 'safety/threat' evaluation, we will try to communicate face-to-face as much as possible. We will invite people to share only what feels safe and respect their pace. We will make it easy to leave (and return to) discussions, agreeing 'time out' signals when needed (e.g. in groups). We will be aware of our own reactions and the need to be authentic, connected and hold appropriate boundaries. We will ensure safety protocols are in place to deal with current risks, support is available for any distress/flashbacks and signposting is available before and after conversations about abuse (Perot et al., 2018)

One final point made by the Charter is that co-produced work with victim survivors should be creative and joyful and celebrate sucesses and achievements:

Abuse is corrosive, restrictive and soul-destroying. Engagement should be a creative process. Good engagement focuses on positive experiences and strengths as well as negative ones and can increase capacity for joy, creativity and imagination. Where appropriate, projects should include elements of fun and celebration of achievements and landmarks in the lives of individuals and in survivor groups and wider social justice movements for survivors.(Perot et al., 2018)

Conclusions

In order to gain an overview of existing principles and guidance for undertaking co-produced research with victim survivors of domestic volence a comprehensive literature search was undertaken. The search only located two frameworks which directly addressed these issues in the context of co-produced research. In addition, a number of doccuments about principles for ethical research with participants who are victim survivors of domestic violence or ethical co-production of services and policies provided useful were located and provide relevant background and context.

Throughout the review it became evident that there is considerable agreement about the key factors which are important to consider when undertaking ethical research and engagement with victim survivors as research participants. It was also clear that many of these principles should also inform ethical co-production with the same group.

Considerable literature has focussed on assessing whether adequate processes are in place to protect the safety and wellbeing of victim survivors and the management of risks of research with victim survivors (Ellsberg & Heise, 2002; Gabriel, James, Cronin-Davis, Tizro, Beetham, Hullock, & Raynar, 2017; World Health Organization, 2001). However the literature about co-production which is being driven by victim survivor advocacy groups has called for this discussion to be expanded to consider not only how to ensure research participant safety is protected but also how to harness the potential transformative benefits for participants and increase research quality (Nnawulezi, Lippy, Serrata, & Rodriguez, 2018). Further exploration of how this can be achieved and practical guidance for researchers is identified by the review as an area that needs additional exploration.

A number of the frameworks for ethical engagement of victim survivors contain useful templates, checklists and questions for reflection. The development of similar resources for the specific challenges faced by researchers interested in engaging in ethical co-production with victim survivors has also been identified as a gap in current resources. In addition, some examples of how the principles that have been identified as most important might look when applied within research projects at the mirco level (such as how meetings are run, ethical dissemination plans and how power dynamics are addressed and how decision-making is made more transparent and democratic) are identified as examples where more granular support and advice would be beneficial. The findings of this review of the literature support the need for a specific framework for coproduction of research with victim survivors of domestic, family and sexual violence.

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