



The Victorian
Collaborative Centre
For Mental Health & Wellbeing

Working it out together

Toolkit

A toolkit and workbook for Lived
Experienced-centred mental
health and wellbeing
research practice



wellways



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Preface

This project was completed by Wellways Australia for the Victorian Collaborative Centre for Mental Health and Wellbeing.

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Acknowledgment of Country

The Victorian Collaborative Centre for Mental Health and Wellbeing (the Collaborative Centre) acknowledges with deep respect all First Nations people and Traditional Owner groups within Victoria. We recognise their enduring connection to Country, Culture, and Kin, a connection that has been nurtured for thousands of years. We acknowledge government's role in the devastating impacts of colonisation, the displacement and dispossession of First Nations people, and the ongoing social, emotional, biological and political consequences. We pay our deepest respects to elders past and present, recognising their ongoing resilience, wisdom, and leadership. We acknowledge that this land was, is, and always will be Aboriginal land.

Recognition of Lived Experience

We acknowledge people with Lived and Living Experiences of mental ill-health and psychological distress and the experiences of people who have been, and are, families, carers, supporters and kin. We are grateful for their expertise and generosity in guiding the Collaborative Centre's work.

Some of the most powerful evidence of the Royal Commission into Victoria's Mental Health System came from the personal experiences of people living with mental ill-health, their families, carers, supporters and kin. There has been extraordinary determination and courage as people have revisited painful memories in the hope of shaping a better future for themselves and others. The Collaborative Centre celebrates, values and welcomes people of all backgrounds, genders, sexualities, cultures, religions, ages, bodies and abilities.

Dr Cat Commentary



Hi everyone, I'm Dr Catherine Brasier (you can call me Cat). I am a Consumer Academic and was the Project Lead for this toolkit and workbook, I'll be authoring some commentaries throughout. I've been an active member of the Lived Experience movement since 2006. Before I was a Consumer Academic, I was a community mental health worker. I'm now the National Manager of Evaluation and Research (Lived Experience) at Wellways Australia where we are pioneering participant and Lived Experience driven research.

Executive Summary

Background: Mental health research often reflects the priorities and interests of mental health services and researchers – but is yet to effectively address the needs, priorities and experiences of mental health consumers and families, carers, supporters and kin.

Purpose: This toolkit advocates for Lived Experience-centred research that improves the real-life outcomes and experiences of consumers, families, carers, supporters and kin. It does this by promoting tools and workbook exercises that researchers and people with Lived Experience can work through together.

Scope: This toolkit addresses the skills, knowledge and capabilities that researchers and people with Lived Experience need to conduct Lived Experience-centred research. This includes researchers working in universities and mental health services. These skills, knowledge and capabilities are essential for people in non-designated and designated Lived Experience research roles.

Our method: This project was Lived Experience-led and included people working from consumer, family, carer, supporter, kin and intersectional perspectives. We combined traditional research methods with co-production/design and product development. We held three translational Design Expert Advisory Groups (n = 25) (consumers/ families, carers, supporters and kin/researchers/services) and Expert Taskforce consultations that included focus groups with consumers (n = 8) and carers, family, supporters and kin (n = 8) and other consultations.

In this toolkit, we cover:

Chapter One: The critical value of Lived Experience-centred research. This chapter presents an introduction to the pivotal and life-changing impact of engaging people with Lived Experience as the leaders and creators of research.

Chapter Two: Our key tools. Presents the key tools that underlie this toolkit including Wellways six steps of the research life cycle, Working It Out Together research action list and a Lived Experience-centred research reporting guideline.

Chapter Three: Implementing Lived Experience-centred research. This chapter explores how to integrate Lived Experience throughout the research life cycle to “work it out together”:



Chapter Four: Evaluating the impact of authentic Lived Experience-centred research. This chapter discusses how researchers can track and evaluate how they have engaged people with Lived Experience in their research project, and the degree to which this has been integrated into the research.

Conclusion: The project demonstrates that “working it out together” is the key to success. It showed that Lived Experience expertise is central to producing mental health research that can understand and improve the life-changing outcomes of consumers, families, carers, supporters and kin. This project drew on a vast range of research and engagement skills, techniques and expertise. We recognised that many of these cannot be achieved through traditional research training alone. For example, the capabilities used to create safe spaces and respond to the impact of trauma/distress is essential to all researchers and requires intentional development in both Lived and non-Lived Experience researchers.

Leading with Lived Experience: Our method for creating this toolkit

The “Working It Out Together” project team took a “walk-the-walk” approach to this project. We used a method that combined traditional research methods with Lived Experience-centred design and product development. This project was Lived Experience-led, it included Lived Experience leadership from the Collaborative Centre, Wellways Australia and La Trobe University. It included people working from designated consumer, family, carer, supporter, kin and intersectional perspectives. The method we used included these Lived Experience-centred steps:

- 1) Connected with key stakeholders/partners and undertook an initial co-design phase
- 2) Validated that we had identified a research question that was important to people who have Lived Experience, researchers and people working in mental health services (i.e. Design Expert Advisory Group and Expert Taskforce)
- 3) Validated that our understanding of the research question reflects the experiences and wisdom of people who have Lived Experience, researchers and people working in mental health services (i.e. Design Expert Advisory Group and Expert Taskforce)
- 4) Explored and developed the power sharing and accountability processes used in the project
- 5) Tested, reviewed and developed the toolkit and workbook exercises through rigorous Lived Experience-centred methods, using a product development mindset
- 6) Evaluated the impact of Lived Experience leadership and engagement in this project through feedback, accountability measures (i.e. Lived Experience Action Log), and reported the findings back to the Design Expert Advisory Group, Executive Sponsor and Key Stakeholder (the Collaborative Centre)

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Chapter One: The Critical Value of Lived Experience-centred Research

Overview

This chapter establishes the importance of mental health research that engages people with Lived Experience as active, empowered creators and leaders. It demonstrates how this will improve the quality and impact of research outputs. Each sub-section focuses on a core knowledge, skill or capability:

- Defines and explores Lived Experience-centred research
- Provides an overview of why Lived Experience leadership is critical to world class mental health research
- Explores what we know about how people with Lived Experience lead, create and share research
- Advocates for greater Lived Experience leadership and engagement in mental health research

What are the key takeaways from this chapter?

Advocate – People with Lived Experience hold the key to creating life-changing mental health research. Nothing about us, without us!

Implement – People with Lived Experience can play many roles in developing and implementing research

Evaluate – It is important to be authentic and transparent about how Lived Experience is incorporated into research projects

Dr Cat Commentary



The term “Lived Experience” can be very confusing and can be co-opted by researchers and mental health workers to strengthen their position in a professional or academic argument, even when their overall position is not in line with the experiences of people who use mental health services or Lived Experience values. It can also be hard to tell what Lived Experience is being referred to (e.g. consumers, families, carers, supporters and kin, alcohol and other drug use, disability etc.).

I recommend using strong scientific reporting skills to state “Lived Experience of **what?**” E.g. In this study, we recruited 10 participants who identified as having Lived and Living Experience of both alcohol use and mental health service use.

What is Lived Experience-centred research?

Definition Box 1. What do we mean by Lived Experience?

What do we mean by ‘Lived Experience’?

Lived Experience refers to a significant and life-changing direct experience of mental health challenges, distress or trauma that is experienced by a person. It acknowledges the unique insights and awareness that comes from these experiences of adversity and healing. It encompasses experiences of: i) accessing mental health and wellbeing services (i.e. consumer Lived Experience); and ii) supporting someone who experiences of mental health challenges, distress or trauma (i.e. family, carer, supporter and kin Lived Experience).

Lived Experience-centred research engages mental health consumers, families, carers, supporters and kin as active and empowered leaders and creators in the research process. It directly addresses their needs, expectations and priorities and attests to the impact of mental health services/supports/systems on them. Lived Experience-centred research can be conducted by people working in universities, mental health services and Lived Experience organisations; ideally these key stakeholders work together.

Research teams may be comprised of people who have a spectrum of Lived Experience. There are many ways of thinking about this, here is one example:

1. Lived Experience **designated** roles/perspectives (All in! All the time!)
2. People who may be **informed** by personal experiences but may also draw on other disciplines/role requirements/professional codes of conduct (etc.)
3. People who have had personal experiences relating to mental health but whose work is **not intentionally informed** by this or does not speak to it
4. People who **do not have a Lived Experience** that speaks to the research question

Designated Lived Experience research roles

Researchers working from a designated Lived Experience perspective commit to working solely from that point-of-view, fully embodying Lived Experience values and practices. This is distinct from researchers who may feel that they are informed by their experience of distress/caring but who may also draw on knowledge bases, practices and experiences that are not consistent with the Lived Experience perspective (e.g. clinical/medical training, role expectations, discipline codes of conduct, etc.). Either way, this should be communicated transparently and authentically; both require forms of Lived Experience training/support (e.g. Sharing Safely training, Lived Experience supervision, etc.).

Researchers working from a designated Lived Experience perspective may contribute to research that is Lived Experience-led or work in multi-disciplinary research teams. Their expertise demonstrates a deep understanding of each of these domains:

1. Their own personal experience of mental health and/or caring
2. Their understanding of other people's Lived Experiences
3. Lived Experience values and practices
4. The history of the Lived Experience movement – including the impact of the systemic and social factors

Lived Experience-centred research is distinct from Lived Experience-led and owned research. This is an independent discipline or area of expertise, characterised by its own knowledge base, ways of working, and professional expectations. It put control all aspects of the research (e.g. from design through to implementation) in the hands of people with Lived Experience (1). The flow of Lived Experience expertise may grow and change throughout the research life cycle, this should be supported accordingly.

Lived Experience leadership is critical to world class mental health research

In Australia and internationally, mental health consumers, families, carers, supporters and kin play little to no role in most mental health research; this contributes to poor outcomes and experiences. Peer reviewed literature and health policy have been advocating for people with Lived Experience to be active leaders and producers of research for more than 20 years, but there has been insufficient change in mainstream research practices (2-6).

The growing consumer and family, carer, supporter and kin movements have increased people's opportunities to influence change from inside and outside the system (7). The ongoing dedication of grassroots activists, advocates and allies has succeeded in cementing the importance of listening to people with Lived Experience (8). Despite this, people with Lived Experience are not fully satisfied with their level of leadership in research, although some progress is being made (1, 9-11).

In practice, Lived Experience, research and service delivery often operate independently. This 'siloing' creates bubbles of knowledge, skills and experiences which create barriers to improving people's real-world outcomes. Lived Experience, research and service delivery all need to work together to improve the lives of consumers and families, carers, supporters and kin. They each hold unique pieces of the puzzle but safe and effective ways of working together have not yet been fully established.

What we know so far about how people with Lived Experience lead, create and share research

A Lived Experience-led rapid scoping review was conducted by Wellways Australia in 2024 for the Victorian Collaborative Centre for Mental Health and Wellbeing (12). This review identified 81 peer-reviewed and grey publications and consulted with 23 people. Publications included Lived Experience-led and non-Lived Experience-led literature. Consultations included consumers, family/carer/supporter/kin, Lived Experience leaders, First Nations people and senior service delivery allies.

The review and consultations illustrated several important themes:

1. **The people most impacted by mental health research and evaluation are often left out of the research process.** For example, people with Lived Experience were often not involved in defining the “research question” and did not learn the outcome of the project.
2. **People with Lived Experience (including peer workers) are often left out of “technical activities”.** For example, people with Lived Experience often were not included during design, data collection or analysis. Although they could become more involved in these tasks through capability building, training and education, mentoring and opportunities to build these skills on the job.
3. **Support and mentoring for people with Lived Experience who choose to undertake formal research pathways is key.** Researchers in universities and health services will need Lived Experience values-based support to become impactful and innovative. Researchers with Lived Experience (including members of Expert Advisory Groups and other experts) require access to Lived Experience and research support.
4. **Intersectionality and accessibility were not fully incorporated into research projects or reported sufficiently.**

Overall, this scoping review concluded that while a significant philosophical and advocacy argument about the importance of people with Lived Experience leading, creating and sharing research has been made, there was limited information about how this should be done and what tools could be used; this toolkit responds directly to this conclusion.

Advocacy reflection

We often think of advocacy and research as very separate pursuits. However, this toolkit is a piece of advocacy and a living demonstration of how we are all connected in our goal to create systemic change and disruption of the status quo. Meaningful change requires action both within and outside existing mental health and wellbeing systems. Historically, evaluation and research have occupied a position of authority over people, communities and cultures they study (e.g. First Nations research), this power imbalance has perpetuated discrimination and exclusion (13). Research is an important complement to advocacy, by working together we are developing a mental health system where everyone has agency in driving change and where people with Lived Experience can do this on their own terms.

Chapter Two: Our Key Tools

Overview

This chapter presents the key tools that underpin this toolkit and workbook. It includes:

- Wellways six steps of the research life cycle
- Working It Out Together research action list
- A Lived Experience-centred research reporting guideline
- Lived Experience Action Log

What are the key takeaways from this chapter?

Advocate – Mental health researchers can create impactful research by using processes, tools and methods that are Lived Experience-centred

Implement – Lived Experience-centred tools are a practical way to develop researcher’s capabilities so that they can develop and implement Lived Experience-centred research

Evaluate – The tools in this section provide a basis for tracking and monitoring how Lived Experience-centred research is developed, implemented and reported

Dr Cat Commentary



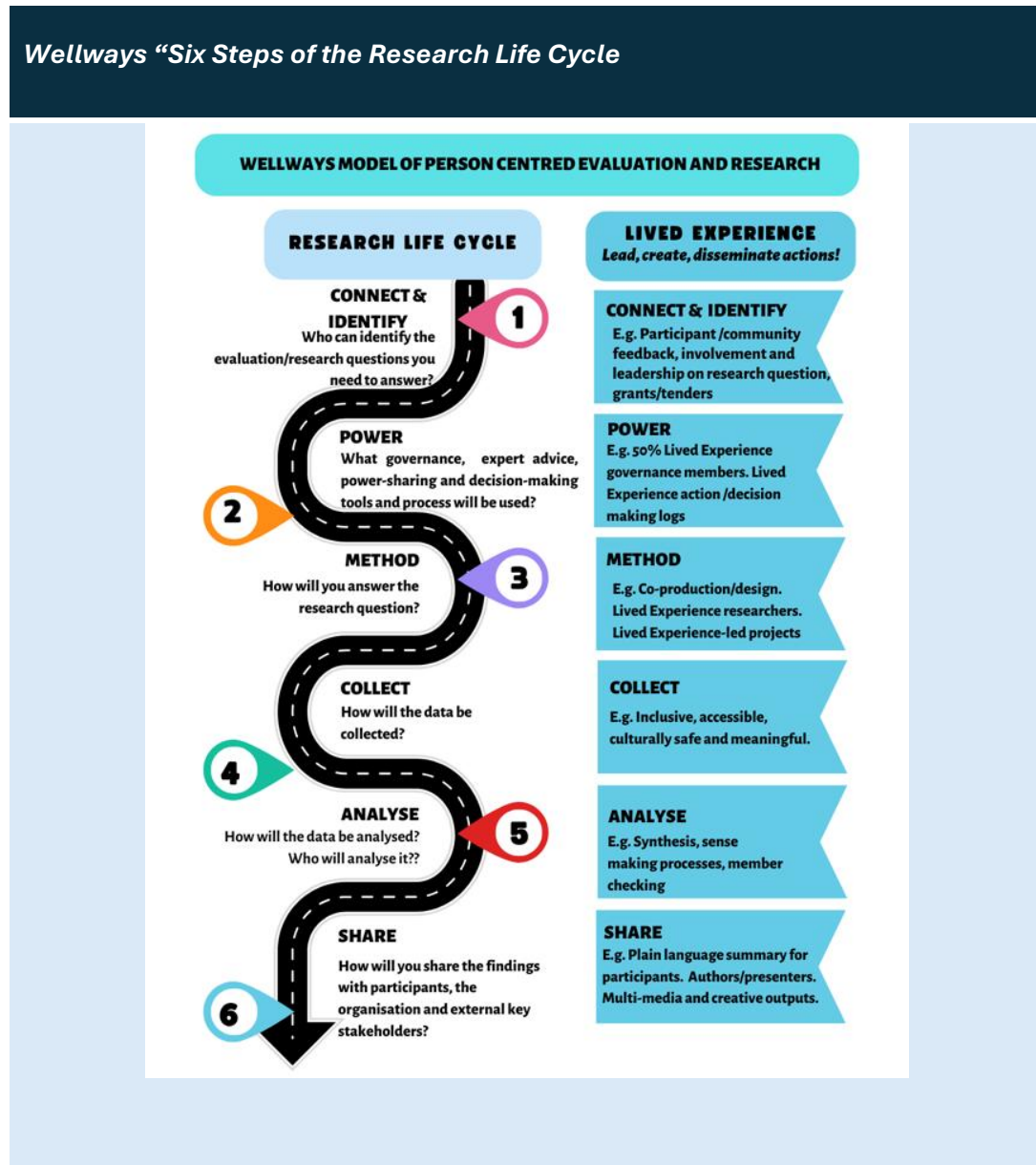
It's really important that we are clear and transparent about "how we know what we know", this is a part of how we establish trust and integrity. It's great to role model and support people to express how they are using their Lived Experience in a way that feels right for them. This should be done while honouring their absolute right to choose what they share – it's a balance.

The use of Lived Experience in research challenges how experiences of distress have been reduced to categories (e.g. diagnostic language – schizophrenia, depression, mania, etc.) instead of using language and concepts that have come from the people who have had that experience. I find this as profoundly othering. Reading mental health literature, I am often shocked by how comfortable we are talking about fellow humans in a way that ignores that we are fundamentally the same – with beating hearts and curious minds. I talk about this in my article: "Constructing recovery: A Lived Experience and post-structuralist exploration of how the meaning of personal recovery and rehabilitation has changed over time" (14).

Wellways “Six Steps of the Research Life Cycle”

This model is based on our scoping review (12) that identified a number of core stages. It echoes previous guidelines and frameworks (15-17).

Figure 1. Wellways “Six Steps of the Research Life Cycle”



Working It Out Together research Action list

These Actions build upon Wellways “Six Steps of the Research Life Cycle” (see Figure 1). They are detailed in the following chapters alongside related information and workbook exercises.

STAGE ONE: CONNECT & IDENTIFY

Action 1. Create a Lived Experience intention and impact statement

Action 2. Harness community and industry relationships

Action 3. Identify a research question and validate that your research question is important to your community

Action 4. Form a Lived Experience-centred research team

STAGE TWO: POWER & DECISION-MAKING

Action 5. Embed Lived Experience and intersectional expertise throughout the project

Action 6. Create a plan to ensure that your research project is accessible and inclusive

Action 7. Create a Lived Experience-centred research culture and processes that unites the team

Action 8. Create a plan to support the mental health and wellbeing of all members of the research team

Action 9. Create a plan detailing how the research team shares power and makes decisions

STAGE THREE: METHOD

Action 10. Develop a research method that is rigorous and Lived Experience-centred

Action 11. Explore Lived Experience and participatory research methods

Action 12. Explore Expert Advisory and Decision-Making Groups, committees and governance groups

STAGE FOUR: DATA COLLECTION

Action 13. Create a Lived Experience-centred data collection plan

STAGE FIVE: DATA ANALYSIS

Action 14. Create a Lived Experience-centred data analysis plan

STAGE SIX: SHARING

Action 15. Creating a Lived Experience-centred dissemination plan

Action 16. Report your research project in a way that is Lived Experience-centred and rigorous

STAGE SEVEN: EVALUATION & IMPACT

Action 17. Evaluate the impact of engaging people with Lived Experience as leaders and active contributors in your research project

Lived Experience Action Log

Below is a copy of the of Lived Experience Action Log (with example content), we used this in our Expert Advisory Groups. Please see our [Case Study](#), the template below and the [“Working it out together: A toolkit and workbook for Lived Experience-centred mental health and wellbeing research practice”](#) for more information.

Table 1. Lived Experience action log

Date	Meeting / Feedback source	Action	Recommendation / reflection	Person / team accountable	Action Progress	Outcome – Part A	Outcome – Part B – Complete for all items that were not actioned with a brief explanation
E.g. 2.2.25	EAG 1	Co-create power and decision-making plan	Are we missing any key voices (e.g. First Nations)	Project Leads	In progress		
E.g. 5.6.25	EAG 2	Recruit Consumer Co-Chair for EAG	This project should have a consumer and family / carers / supporter / kin Co-Chair	EAG Meeting Chair	Consumer Co-Chair to attend next EAG	Complete	NA
E.g. 2.7.25	EAG 3	Add a phase 3 literature review	This project should explore an additional literature review	Project Lead and EAG Chair	Partially addressed	Future recommendation	This does not fit the scope of this project, we recommend it for future projects

Lived Experience-centred research reporting guidelines

This build on the “Working It Out Together” research [Action list](#) and [Wellways “Six Steps of the Research Life Cycle”](#) (see Figure 1). This tool requires researchers to be accountable for how they have integrated Lived Experience in their research project and how they communicate this. This tool is an important guideline for reports, publications and grants for both research teams and assessors/funders. This reporting guideline mirrors the structure of peer reviewed paper/research report and should be used in conjunction with the workbook exercise and [“Evaluating how Lived Experience was integrated throughout a research project”](#) (Table 4) which summarises the impact of Lived Experience across the stages and actions present in this toolkit.

Table 2. “Working it Out Together”- Our Lived Experience-centred research reporting guideline

Section/Topic	Item No	Checklist item	Reported
TITLE & ABSTRACT			
Title and abstract	1a	Acknowledges how people with Lived Experience have contributed to the design and delivery of the research project in the abstract (e.g. design, methods, results and conclusions).	
Background and objectives	2a	Articulates the value and importance of Lived Experience by connecting this to the study’s rationale.	
	2b	Establishes how this research responds to the experiences, priorities and preferences of people who have experienced mental distress and/or families, carers, supporters and kin.	
	2c	Reports and outlines underlying conceptual frameworks and their relationship to Lived Experience, including any limitations/contradictions.	
	2d	Reports aims, objectives or hypotheses as Lived Experience-centred.	
Project life cycle	3a	The description of the research method specifies how Lived Experience knowledge, engagement and expertise was utilised throughout the study. The role/contribution of people with Lived Experience is reported authentically throughout the research project life cycle including:	
	3b	<ul style="list-style-type: none"> • In the identification and validation of the research question. 	
	3c	<ul style="list-style-type: none"> • In the formation and membership of the research team. 	
	3d	<ul style="list-style-type: none"> • Leadership, power and decision-making processes. 	

	3e	<ul style="list-style-type: none"> The development of research and project methods (including the use of participatory/co-design/co-production methods). 	
	3f	<ul style="list-style-type: none"> Data collection. 	
	3g	<ul style="list-style-type: none"> Data analysis, sensemaking and validating the findings. 	
	3h	<ul style="list-style-type: none"> Knowledge sharing, authorship and dissemination. 	
	3i	Description of other research processes that supported Lived Experience engagement and leadership (e.g. regular project meetings, mentoring, research training and support, community partnership, etc.).	
	3j	Description of how intersectionality, accessibility and inclusion were supported within the research team/project.	
Lived Experience in Governance, Committees and Expert Advisory Groups	4a	Utilised Lived Experience Experts (i.e. in addition to study participants).	
	4b	Details the timing, frequency, delivery (hybrid/face-to-face) and other key details of these meetings.	
	4c	Details the support available to the Expert Advisory/Decision-Making Group/Lived Experience Experts (including family/carer/supporter/kin, and consumer specific peer support).	
	4d	Detail how these roles/participation were remunerated.	
	4e	Describes the selection process for these roles.	
	4f	Details the mechanisms (e.g. Terms of Reference) underpinning the governance/committee/advisory group that promoted or limited power and decision-making in the group, and on the broader project.	
	4g	Reports the membership including any Lived Experience and intersectional designated roles (Culturally and linguistically diverse, disability, First Nations, etc.).	
	4h	Reports who Chaired/Co-Chaired the meetings and if they were Lived Experience designated roles.	
Research team – Reflexivity statement	5a	Identifies if members of the research team are working from a designated Lived Experience-perspective (i.e. all contributions are in line with Lived Experience values and practices).	
	5b	Reflects the on how the Lived Experience in the research team contributes a deep understanding of a personal recovery journey, the experience of the broader Lived Experience community and is underpinned by Lived Experience values and history as a social movement. Noting any appropriate limitations or strengths.	
	5c	Reflects on other life experiences experienced by the research team that may impact the study (e.g. discipline/training, reasons for doing the study, values, biases, benefits of doing the study, etc.).	

	5d	Details how Lived Experience members of the team will be supported (e.g. access to peer support/debrief, cultural integrity, access and inclusion).	
	5e	Identifies the strengths (e.g. Lived Experience training, leadership experience, previous Lived Experience contributions and community involvement) and limitations (e.g. starting late in the project, limited diversity or accessibility, lack of peer support) of the team as a whole.	
Results	6a	The results are reported in a way that is respectful of people with Lived Experience and aligns with Lived Experience values.	
Translating research into practice	7a	The findings are contextualised in relation to Lived Experience values, principles and priorities.	
	7b	Establishes how the research can improve the real-life outcomes for consumers, family/carer/supporter/kin.	
	7c	Establishes how this research can be translated to improve mental health services, systems and supports.	
Evaluate and report	8a	Establishes the conclusion that directly addresses the research question and how the findings impact on consumers and family/carer/supporter/kin.	

Chapter Three: Implementing Lived Experience-centred Research

Overview

This chapter provides information and **Actions** to support researchers to design and conduct Lived Experience-centred research. It explores:

- How to connect to the people who can help you identify your research question
- How to address power and decision-making
- How to create a Lived Experience-centred method
- How people with Lived Experience can help with data collection
- How people with Lived Experience can contribute to data analysis and making sense of the findings
- How people with Lived Experience can support the ongoing process of sharing the research projects findings

This chapter will address how projects can evaluate and demonstrate that Lived Experience input has had a meaningful impact on how the research was conducted.

What are the key takeaways from this chapter?

Advocate – People with Lived Experience are deeply capable and can take on new adventures with pride

Implement – “Working It Out Together” promotes how people can participate in developing and implementing research in many ways

Evaluate – This chapter introduces six stages of the research process, plus **Actions** that a research team can take; in the next chapter these become the basis for evaluating how research teams have authentically become Lived Experience-centred

Dr Cat Commentary



Peer reviewed literature often holds an inherent bias and unknowing that can be stigmatising and disconnected from people’s real-life experiences. Connecting to people with Lived Experience in the community can help you create research that reflects their needs, experiences and priorities.

The Lived Experience community is very diverse and holds the wisdom gained from many different experiences. When I am asked to contribute to topics that are outside of my personal Lived Experience, I communicate this and try my best to be clear about “how I know what I know” (e.g. is this something I have experienced personally? Have I learned this from listening to other people’s experiences? Is this what I learned from being a mental health worker? Have I done research on this topic? Is it based on Lived Experience literature, etc?). Honouring the specific Lived Experiences that your research project addresses is vital. It’s OK to acknowledge the limits of what you can speak to. This can create opportunities for new voices to enter the project.

Research Stage One: Connect and Identify



Connect & Identify

Research Life Cycle Stage: 1

Key Question:

Who do you need to collaborate with to identify your research question and create an exceptional research team?

Dr Cat Commentary



I have often heard researchers say that Lived Experience-centred methods “take too long”. However, when researchers are deeply connected to Lived Experience communities and involve us in developing a project, this process is usually much easier. This also leads to more impactful research because people with Lived Experience can identify factors that feel obvious to them that are otherwise routinely missed due to research bias and unknowing.

✓ **Action 1. Create a Lived Experience intention and impact statement**

This section explores the process of identifying your research question and connecting to your community as a process that happens simultaneously. This helps disrupt old patterns of not including people with Lived Experience in project development and grant applications. Research teams should consider how people with Lived Experience will know the project is worth joining (e.g. will the results be "used against them" or be validating?).

Workbook Exercise 1. Creating a Lived Experience intention and impact statement



Creating a Lived Experience intention and impact statement

Gather as a project team and explore these questions:

1. Why is Lived Experience important to this research project?
2. What roles and input will people with Lived Experience have at each step of this project?
3. What would we not know or miss out on if people with Lived Experience were not integrated into this research project?
4. Whose voices and experiences are missing? What is the impact of this?
5. How will this research project help people with Lived Experience in their day-to-day lives?

Are there any questions that your team would like to add?

✓ Action 2. Harness community and industry relationships

Being an authentic participant of the communities that you are interested in impacting through your research is the key to world class mental health research. It is key to establish a shared commitment and mutual benefit across key stakeholders. Potential key stakeholders include Lived Experience organisations and peak bodies, Mental Health services, professional networks, university partnerships, Ph.D and research networks, government. Authentic connections to Lived Experience and intersectional communities are key to identifying and answering impactful research questions.

Workbook Exercise 2. Helpful friends – Connect to the knowledge, skills and expertise you need to excel



Helpful friends – Connect to the knowledge, skills and expertise you need to excel

Who do you need to connect to build the relationships key to your project?

Table 3. Mapping helpful connections

	Skills	Knowledge/Expertise	Capabilities
Lived Experience			
Research			
Service delivery/design			

✓ **Action 3. Identify a research question and validate that it is important to your community**

This builds on our step about developing authentic connections throughout your community, especially with people who have Lived Experience. Too often research questions are developed without asking people with Lived Experience what matters most, or which outcomes are important to them. Based on this your team must be able to identify how their project will be **important**, **original** and **feasible**, as well as **beneficial** and **meaningful** to your community. You need to validate or verify that your research question is important to mental health consumers, families, carers, supporters and kin.

You should also consider intersectional points-of-view and demonstrate its translational potential (i.e. its impact on Lived Experience>research>service delivery/design). This stage may feature a literature review, policy review, engagement with the community and professional networks (etc.) in addition to [Lived Experience input](#) (18).

Workbook Exercise 3. Defining your research gap according to Lived Experience priorities, needs and values



Defining your research gap according to Lived Experience priorities, needs and values

In research we are always trying to show that we are doing something novel and valuable to fund. This exercise establishes this and connects it to Lived Experience and/or the experience and impact using a mental health service.

Gather as a team and discuss – this can become a key planning document:

1. Our research question is important to people with Lived Experience/who use mental health services because...

2. Existing research on this topic tells us that...
3. Research on this topic has (or has not) addressed the priorities and expectations of people with Lived Experience by...
4. Therefore, our research project is important because we will respond to this gap by answering this question...
5. I am confident that this project has the resources and Lived Experience expertise/experience/project staff to complete this project because...
6. Then describe how you will validate your research question. What steps will you take to verify that your research question is important to your community?

Are there any questions that your team would like to add?

✓ **Action 4. Form a Lived Experience-centred research team**

Research grants use a hierarchical structure that is governed by very specific rules (e.g. in most grants you must have a Ph.D and a track record of being awarded and completing research projects/publishing in peer reviewed journals); this creates legitimate barriers for people with Lived Experience. This is also challenging for Lived Experience and ally researchers are prevented from including important Lived Experience experts who do not meet this criterion (19).

Workbook Exercise 4. Articulate how you will integrate Lived Experience and intersectional expertise throughout your research project



Articulate how Lived Experience and expertise is integrated throughout your research project

Write a reflexivity statement. Consider the following:

1. Are members of the research team working from a designated Lived Experience-perspective (i.e. all contributions are in line with Lived Experience values and practices – all the time)?
2. How does the Lived Experience researchers in the team reflect a deep understanding of a personal journey, the experience of the broader Lived Experience community and is underpinned by Lived Experience values and history as a social movement?
3. What other life experiences in the research team may impact/bias the study (e.g. discipline/training, reasons for doing the study, values, biases, benefits of doing the study etc.)?

Are there any questions or reflections that your team would like to add?

Research Stage Two: Power and decision-making



Power Research Life Cycle Stage: 2

Key Question:

How will your study implement Lived Experience-centred power and decisions making processes?

Dr Cat Commentary



Our scoping review noted that there should be a **critical mass** of Lived Experience in the project. For me this is not just about the number of people with Lived Experience in a research team – it also thinks about the **critical distribution of power and privilege**, and the degree to which this will impact decision making. Understanding people’s context is important to addressing power.

What is most important is that research teams need to be clear and transparent about how power will impact how the team runs, acknowledging different levels of power between all members of the research team. This should be discussed routinely, and throughout the project. Tools such as a [Lived Experience Action Log](#) can be used to account for this.

People with Lived Experience can feel like outsiders, that they are outnumbered or that there are explicit and implicit forms of power/influence at play that will limit the impact of their contribution (20). Exploring the role of power and decision-making in a Lived Experience-centred research project is ongoing and iterative. There are complex power imbalances rooted in professional, historical, social and statutory structures. This limits how people with Lived Experience lead, shape and participate in mental health systems and mental health research (21, 22). This impacts how power is distributed and experienced by people with Lived Experience within our research context (23-29).

✓ **Action 5. Embed Lived Experience and intersectional expertise throughout the project**

This section explores the intentional and authentic use of Lived Experience and intersectional expertise in research projects.

Lived Experience perspectives

We introduced some important considerations about how to integrate Lived Experience perspectives in [Chapter One](#). There are lots of ways of thinking about this, in this toolkit we have considered: i) **designated** roles/perspectives; ii) people who may be **informed** by personal experiences but may also draw on other disciplines/role requirements/codes of conduct (etc.); iii) people who have had personal experiences relating to mental health but whose contribution is **not informed** by this on an intentional level; iv) people who **do not have a Lived Experience** that speaks to the research question. Many people have experienced significant periods of mental distress as well as experiences of providing care and support, this is referred to as “dual experiences” or “dual perspectives”. Families, carers, supporters and kin of both mental health and physical health consumers have exceptionally high levels of mental distress (30, 31). Whichever way you describe how Lived Experience is comprised in the research team, it is essential to be transparent about how you know what you know and what role this will play in you project.

Intersectionality

Intersectionality is a framework for understanding how various aspects of a person's identity, such as gender, race, sexuality and class intersect and interact to create unique or different experiences of discrimination and privilege (32). It acknowledges that these overlapping identities create different experiences for individuals and groups, and can compound the effects of marginalisation and inequity (33). Mental health consumers and families, carers, supporters and kin may find that their experience of accessing and receiving support is compounded by the impact of other forms of intersectionality (e.g. lack of accessibility, preferring to speak a language other than English, gendered systems, lack of cultural integrity). Research practices can perpetuate this way. For example, researchers can do things that are exclusory or unwelcoming (e.g. hold meetings on Zoom, formal settings, rigid rules and a lack of cultural integrity). Research often relies on extensive written and spoken conversations that are in English, even though the Australian Bureau of Statistics reports that 22.8% of Australians speak a language other than English at home (34).

First Nations people and communities

First Nations people experience mental health challenges in greater numbers than the general Australian public (35). Social and Emotional Wellbeing is fundamental to First Nations mental health, it views health holistically by relating it to family, community, culture, spirituality and country, as opposed to Western worldviews that focus on the individual (36). Effective mental health approaches for First Nations people must take a comprehensive approach, incorporating both traditional healing practices and traditional mental health care (37, 38). A major barrier to accessing mental health care is intergenerational trauma stemming from colonisation, forced removals, and cultural loss, creating mistrust toward government services (39-41). First Nations communities and cultural integrity (37, 38, 42) should be incorporated into mental health research, service design and delivery to make services more inclusive, responsive, respectful and accountable (15). Community-controlled research, where First Nations people are active participants and leaders, also builds trust and leads to more relevant mental health services and research is a fundamental step (37, 38, 40).

Workbook Exercise 5. Mapping opportunities to integrate Lived Experience and intersectional leadership and wisdom throughout the research project



Mapping opportunities to integrate Lived Experience and intersectional leadership and wisdom throughout the research project.

Gather as a team and discuss these questions. This is an important step in gaining clarity around the Lived Experience and intersectional relationships that will underpin how you answer your research question.

1. Our research question directly asks about the experiences/impact of services on:
 - a) Mental health consumers
 - b) Mental health families, carers, supporters and kin
 - c) Both mental health consumers **and** their families, carers, supporters and kin
 - d) Intersectional communities and experiences
2. Within this Lived Experience cohort (consumer/families, carers, supporters and kin) our research question has a specific focus on (*respond to any that relate*):

- e) A specific form of distress/caring (e.g. responding to trauma, psychosis, depression, etc.)?
- f) Intersectional experiences/perspectives
- g) Location (e.g. country, state, catchment/service area)
- h) Type of mental health service (e.g. public/private, residential, outreach or youth, adult, older adult)
- i) The specific program, service, support, organisation, system (e.g. the specific program being evaluated)

Are there any questions that your team would like to add?

✓ **Action 6. Create a plan to ensure that your research project is accessible and inclusive**

Many people find participating in research inaccessible and not inclusive. Research projects frequently require levels of literacy that can exclude people who have great things to share. The very way we conduct research can exclude people and bias/limit the results. Our Expert Taskforce consultations identified that this can be because researchers often seem unapproachable, or communicate in a way that feels intimidating, alienating or objectifying. Research designs are often inaccessible (or inappropriate) for people who are First Nations, culturally and linguistically diverse, who identify as LGBTIQ+SB (Lesbian, Gay, Bisexual, Transgender, Intersex, Queer, Asexual, Sistergirl, Brotherboy), who are impacted by caring/support duties, are located in rural/remote locations or restrictive service environments (e.g. prison, inpatient units, etc.). Many well-accepted research practices exclude and potentially discriminate against people (e.g. excluding people who do not want to be audio recorded during data collection, lack of support for those who speak a language other than English or who need support reading and writing, or through a lack of cultural integrity).

Case Study 1. Key resources for accessibility and inclusion

Key resources for accessibility and inclusion

The United Nations Disability Communications Guidelines provide helpful and practical guidance on how projects can communicate and share information in a way that is accessible (https://www.un.org/sites/un2.un.org/files/un_disability-inclusive_communication_guidelines.pdf).

The Accessibility and Inclusion Strategy (the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with a Disability) also includes a focus on women and girls (<https://disability.royalcommission.gov.au/publications/accessibility-and-inclusion-strategy>).

National Disability Insurance Scheme (NDIS) Culturally and Linguistically Diverse Strategy provides foundational information about how the NDIS engages with diverse communities. It includes translated and Easy Read versions (<https://www.ndis.gov.au/about-us/strategies/cultural-and-linguistic-diversity-strategy>).

Workbook Exercise 6. Articulate how you will embed access and inclusion throughout your project



Articulate how you will embed access and inclusion throughout your project

Gather as a team to workshop the following questions:

1. What are organisational, industry and government guidelines about access and inclusion that should inform your research project?
2. What resources and expertise are available to enact these principles and guides?
3. Have you included expertise addressing this in your research team?

Are there any questions that your team would like to add?

✓ **Action 7. Create a Lived Experience-centred research culture and processes that unites the team**

Your research plan should foster connection and sharing, often people with Lived Experience are left out of this step (8, 13). Establish a strong Lived Experience team culture through dynamic and meaningful engagement. For example, email discussions, shared ideation (e.g. MiroBoard and other digital technologies) and additional project team meetings/workshops (18).

Workbook Exercise 7. Create a Lived Experience and participant-centred research plan



Lived Experience and participant-centred research plan

Gather as a project team and address how the team will:

- ✓ Create a translational plan (i.e. Lived Experience, research, service delivery/development) that details how the project team will embed this wisdom throughout the project; this should be complimented with an accountability tool (See [Action Log](#))
- ✓ Start a collaborative communication and work plan that outlines how the project team members will work together that is inclusive, accessible and honours cultural integrity
- ✓ Create a power sharing and decision-making process for the project team
- ✓ Co-create safety and cultural integrity principles and practices
- ✓ Confirm the function of any Expert Advisory/Decision-Making Group, Governance, Committee or external expertise in the development and completion of the project

Are there any stages or tasks that your team would like to add?

✓ **Action 8. Create a plan to support the mental health and wellbeing of all members of the research project**

Bring the team together in a supported and trauma informed way to share their thoughts and feelings about how power dynamics and potential imbalances could impact the team, including in decision-making. This should be a process and discussion which continues and evolves throughout the project. Creating a nest of supports to ensure that all members of the team (including Expert Advisory Group members, external Lived Experience consultants etc.) feel supported is key. This draws on our discussion about supporting [Lived Experience](#), [accessibility and inclusion](#), and cultural integrity.

Workbook Exercise 8. A mental health and wellbeing plan for the research project members



A mental health and wellbeing plan for the research project members

Gather as a project team and write a plan of how the team will address this. Consider when and how this will be reviewed throughout the project.

A ‘whole of person’ approach to support the research team’s wellbeing could include:

- ✓ Psychological safety
- ✓ Mental health supports
- ✓ Lived Experience specific supports
- ✓ Cultural integrity practices
- ✓ Accessibility and practical supports

Are there any areas that your team would like to add?

Case Study 2. Working It Out Together – How we supported mental health and wellbeing in our project

Working It Out Together – How we supported mental health and wellbeing in our project

In this project we implemented an integrated and comprehensive plan to support wellbeing, including cultural integrity and social and emotional wellbeing. This included:

- Personal approach/invitation to participate
- Flexible participation options
- Checking in and being transparent about how people utilise their Lived Experience and/or intersectional perspectives
- Meeting face-to-face for kick-off and final Design Expert Advisory Group
- First Nations, cultural and linguistic diversity, LGBTIQ+SB and Lived Experience project leads, project team and expertise
- Trauma-informed practice
- Brave space plans and time to connect
- Debrief options (consumers and families, carers, supporters and kin specific)
- Peak body connections and support
- Lived Experience peer supervision for the project team
- First Nations project team and Expert Advisory Group members including perspectives from a men's business and women's business perspective.

✓ **Action 9. Create a plan detailing how the research team shares power and makes decisions**

The Lived Experience community has often felt that their inclusion in research is tokenistic or that they lack the power. Many people with Lived Experience are excluded from leading grants due to a lack of track record or Ph.D, and may feel “overruled”, ignored or misunderstood in research teams. It is important to actively explore how power and decision-making is experienced by your team, especially those with Lived Experience and/or intersectional perspectives. To explore how this impacts your research project you can check out some great resources and checklists (43-45) (refer to the Research Toolkit on page 68).

Workbook Exercise 9. Understanding how power impacts your research team



Understanding how power impacts your research team

Acknowledging the legacy of current and historical power differences, and how they impact your research project is important. Sit down with your team and reflect on how this might effect your research. You may like to consider:

1. Lived Experience (including dual consumer and family, carer, supporter and kin experiences/perspectives)
2. Intersectional experiences (e.g. First Nations, cultural/language diversity, etc.)
3. Accessibility (e.g. neurodiversity, physical health differences, etc.)
4. Other forms of marginalisation, stigma and exclusion
5. Forms of explicit and implicit privilege/power (e.g. role in the research team, organisational clout, gender, age, seniority, etc.)

Are there any areas that your team would like to add?

[Accountability tools](#) can track the integration of Lived Experience throughout the research process and provide a record of how their expertise was (or was not used), see Case Study 3:

Case Study 3. How did the Working It Out Together project team develop power sharing and decision-making processes?

How did the Working It Out Together project team develop power sharing and decision making processes?

Step 1 – We developed a transparent power sharing process with our key stakeholders to ensure that we were accountable for how we included the input of our Expert Advisory Groups. This process was shared on an info sheet with the Expert Advisory Group members and discussed in the first meeting.

Step 2 – All actions, reflections and recommendations were recorded in the Lived Experience Action log during the meeting as a part of minute-taking.

EAG	Actions, recommendations and reflections - summary	Person/Project team accountable	Action progress	Outcome – Part A	Outcome – Part B – Complete for items that were not actioned – state reason
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[Click here to go to the Lived Experience Action Log template.](#)

Step 3 – After the Expert Advisory Group meeting these actions, reflections and recommendations were compiled, reviewed and summarised by members of the project team and the Lived Experience Project Lead. This was then shared with the key stakeholder and Expert Advisory Group members as a part of the meeting minutes.

EAG	Actions, recommendations and reflections - summary	Person/Project team accountable	Action progress	Outcome – Part A	Outcome – Part B – Complete for items that were not actioned – state reason
EAG 3	Co-design/co-production and way of working together are important	Project Lead/Team	Partially addressed	Future treasures	This is introduced in the toolkit/report but worthy of a separate deep dive/tools
EAG 3	The importance of relationships in the research team and sharing/learning from each other in EAG	Project Lead/Team	In toolkit and report	Complete	
EAG 3	Negotiating what participants and researchers wanted from coproduction, what are the limits/boundaries/time/resources	Project Lead/Team	In toolkit and report	Complete	

Step 4 – The Project Lead and key stakeholders reviewed each action, reflection and recommendation and recorded on the Lived Experience Log and how this information was integrated into the project. If the item was not used in the project, the reason it was not included was noted in the Lived Experience Action Log. This was shared with the Expert Advisory Group members at the end of the project.

A completed example of this is presented in [Chapter Four, see Case Study 4.](#)

Research Stage Three: Method



Method Research Life Cycle Stage: 3

Key Question:

What methods and research processes will you use to answer your research question in a Lived Experience-centred way?

Dr Cat Commentary



As you may have noticed I have not used words like co-production or co-design much in the toolkit so far, instead I tend to describe the process or actions itself. This is very post-structuralist of me – BUT it is also because I get really frustrated and confused when people use co-design or co-production as “black hole” words instead of telling me what it is that they are actually doing. I see this in grants all the time and I always note it in my comments.

Choosing a research method that is right for you can sound overwhelming at the best of times. For researchers who are working on building Lived Experience-centred research teams this can feel like worlds colliding! Negotiating how rigorous research methods and Lived Experience values come together is important and needs to consider what the limits/boundaries/time/resources are available. In our scoping review (12) we found that people with Lived Experience contributed to many stages of the research process. Including formative stages (46, 47), data collection and data analysis (29, 48, 49). Sangill (2019) (48) reported that researchers who had used mental health services were important because of the richness that their perspective brought to the research. Watson, Burgess (29) also reported that their peer-to-peer interviews helped reduce a sense of hierarchy and opened more rich and honest discussions. Researchers should develop and incorporate easy-to-use and unobtrusive tools that could be used by Lived Experience researchers/projects as part of routine service activities (e.g. entry/exit survey or an evaluation wheel), taking into account the participants’ time and potential burden/discomfort (27).

✓ **Action 10. Develop a research method that is rigorous and Lived Experience-centred**

A research method is a rigorous, repeatable and trustworthy approach to collecting, recording and analysing (or making sense of) information that can answer our research question. It must also ensure that the Lived Experience contributors and participants find their involvement purposeful, meaningful and safe (18).

Your method should consider all the **Actions** we have covered so far including intersectionality, accessibility and power sharing. Many of these **Actions** could be integrated into the method and reported alongside traditional study elements (e.g. participant numbers, timepoints, the interventions mode of delivery). For example, the number of Expert Advisory/Decision-Making Groups meetings held, how members were recruited and remunerated are routinely reported in the methods section of peer reviewed papers.

Workbook Exercise 10. Lived Experience-centred method – Brainstorm



Lived Experience-centred method – Brainstorm

*Get together as a team and brainstorm 5 things that you have developed in the **Actions** which should be reported in the Methods section:*

Add your examples here:

✓ **Action 11. Explore Lived Experience and participatory research methods**

Lived Experience-centred (e.g. co-production, co-design) and participatory methods (e.g. citizen scientists) are fundamentally about solving research questions by working with the consumers and families, carers, supports and kin (8, 28, 45). Lived Experience principles and values can be integrated into the method to anchor the project. These methods put a special emphasis on who identifies the research question and how power and decision-making operate through the research project.

Co-production is often considered the gold standard of participatory research. Co-production is about raising the standard of Lived Experience engagement; it is about moving from participation to Lived Experience leadership from the outset (45). It is a creative process in which people with Lived Experience as consumers or families, carers, supporters and kin are central to identifying the research question, designing and delivering the project (28). For co-production to occur researchers, Lived Experience contributors and study participants must be recognised as equals (49, 50), this is why it often features equal or more Lived Experience researchers (51). If this standard is not met the research should be considered research with Lived Experience co-design or Lived Experience engagement rather than co-production research. Often research is presented as co-production or co-design but do not align with the methodology or pre-requisites around power sharing. As Indigo Daya said:

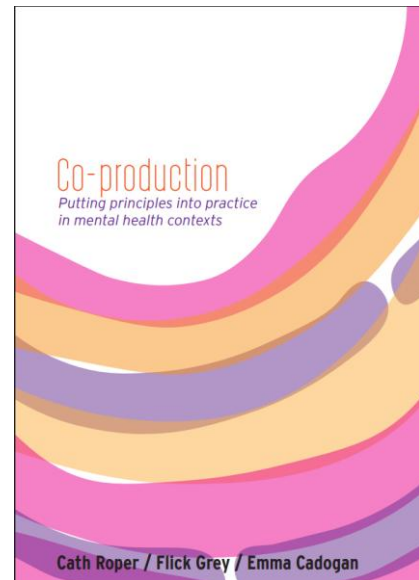
“We’d rather know that you can only do engagement, and then do some good quality engagement, than be part of tokenistic co-design.” Indigo Daya (43)

Co-production: Where has the journey taken us?

A reflection with Cath Roper, Flick Grey and Emma Cadogan – authors of “Co-production: Putting principles into practice in health contexts” (2018)

When “*Co-production: putting principles into practice in health contexts*” was published in 2018 it became a landmark resource for challenging and changing the mental health system by positioning mental health consumers as the true experts. This honoured consumers on-going journey to understand themselves, other people and the world around them, and to create new epistemologies that were experiential, relational and directly linked to consumers experiences.

This piece of work posits that co-productions’ unique focus on the people who were the most impacted by a specific experience (e.g. experiences of seclusion and restraint) is the key to its power. And, in doing so it unsettles and disrupts power dynamics and the traditional mental health system.



The origins and elements of co-production

When considering how co-production was applied in practice and their early experiences of co-production the authors reflected that co-production functions at the level of “citizen control” where:

- Actions and duties were often “smuggled in” to people’s roles
- Co-production activities were conducted with little to no formal budget
- It was propelled by courageous and committed leaders (Lived Experience and ally)
- It operated both outside the system and by utilising institutions (e.g. Universities, governments, etc.)
- It directly propelled change that reflected the needs, experiences and wisdom of consumers
- It was grounded in the real-life experience of mental health consumers and was led by them
- It focused on experiential learning in a deeply relational and transformative environment
- It was supported by allies who approached it with humility and believed they people with Lived Experience held the key to making better mental health services and systems

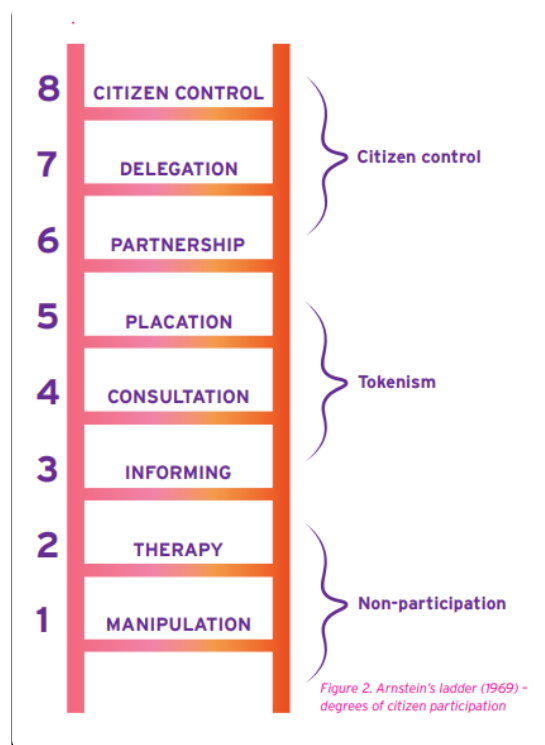
Keeping the spirit and practices of co-production alive

Since the release of this publication, co-production has gained popularity and has gained wide appeal. It is widely seen as a necessity for winning grants, tenders and implementing reform. However, coproduction can be co-opted, captured or misunderstood. This has led to a dilution of the practice where it is often co-opted, or conflated with co-design or other collaborative methods. Due to this, many activities claiming to be co-production actually de-centres consumers, and re-centres other key stakeholders. Compounding these issues is the pace and volume of reform in Victoria which often counters the conditions needed for true co-production (e.g. sufficient time, fostering relational approaches, Lived Experience support/debriefing/mentoring, resourcing, etc). Projects might not be truly consumer-led or reflect the experiences of those who are impacted the most. This is why it is important to use an accountability tools such as Arnstein's ladder (see figure x) to ensure that the research team is being transparent and authentic when describing the level of Lived Experience engagement.

Furthermore, co-production is now often viewed as a research method rather than a meaningful way to generate new knowledge. This has shifted the emphasis back to researchers, losing the elements that made co-production so effective (e.g. equality, openness, flexibility, sharing power, making decisions together).

Assessing your projects level of consumer engagement

It's essential to be transparent and accountable about where you really are on the 'ladder of participation', (Arnstein, 1969) and avoid the temptation of calling something "co-production" when it is consultation, for instance. The ladder can also be used to acknowledge limitations and formulate solutions that could be used in future project.



Workbook Exercise 11. Co-production, co-design and participatory methods – Our top 3 examples!



Co-production, co-design and participatory methods – Our top 3 examples!

Identify the three best examples of co-production, co-design or participatory research that relates to your research question. You may like to use peer reviewed literature, grey literature or other sources:

Add here - You don't have to stop at 3 – are there anymore examples you think are important?

✓ Action 12. Explore Expert Advisory and Decision-Making Groups, committees and governance groups

Dr Cat Commentary



At the end of the day, it is important is that you are clear about how the group runs and that you are transparent with everyone about the level of contribution and decision-making they will have.

Get your group off to a great start by making them feel welcome. One of my main tips for a great in-person meeting is to include the full address (including room number if needed). I usually include a map and some written directions. I always have a number that people can call on the day for support. It is also important to give information about where to park and check in about any accessibility supports. I include this information by email and in the calendar invite. At Wellways Australia we provide a travel support to consumers, families, carers, supporters and kin who are attending in their own time. We remunerate for participation and things like the cost of parking/cab charges.

This section explores Expert Advisory/Decision-Making Groups as a specific methodological component to support Lived Experience-centred research. This was identified as an important gap in our scoping review (12). This section could also inform the formation of other committees and governance groups. Not all research projects will use an Expert Advisory/Decision Making Group, and they should not be used in a tokenistic way.

A well-run Expert Advisory/Decision-Making Group can lead to genuine partnerships between people with Lived Experience, those accessing mental health services and the research team – leading to life-changing research. Expert Advisory/Decision Making Groups should be implemented as early in the research project as possible or the project team risks making major decisions without the benefit of their advice. They can also be used to develop grants, or screen for priority projects by universities and organisations. It is ideal to do this during the **Connect and Identify Stage**. Careful and considered planning is essential for the success of an Expert Advisory/Decision Making Group. It is crucial to provide adequate resources and adhere to sector expectations, including ensuring remuneration policies are aligned with peak body requirements.

Workbook Exercise 12. Articulate how you will develop and support any Expert Advisory/Decision-Making Groups that are a part of the research project



Articulate how you will develop and support any Expert Advisory Groups that are a part of the research project

This section explores some Expert Advisory/Decision-Making Group essentials that you might like to consider. It is ideal to co-create this! Consider following questions:

1. What is the purpose of your Expert Advisory/Decision-Making Group?
2. Will members be contributing to decisions (i.e. Expert Decision-Making Group) or only providing advice (Expert Advisory Group)?
3. How will you invite members to join your Expert Advisory/Decision-Making Group?
4. What pre-reading and preparation is needed (e.g. pre-reading, agenda, remuneration and support information)?
5. How will you approach running an ongoing Expert Advisory/Decision-Making Group?
6. How will you conclude your Expert Advisory/Decision-Making Group? How will you share your findings and future opportunities?

Are there any questions that your team would like to add?

When recruiting Expert Advisory/Decision-Making Group members it is important that they reflect the diversity of the community or topic being researched. You may want to consider:

- Lived Experience co-facilitation to foster a collaborative environment that encourages participation and help minimise power imbalances. Some Expert Advisory/Decision-Making Groups may find it helpful to have a Consumer Co-Chair and a family/carer/supporter/kin Co-Chair
- Use a [Lived Experience Action logs](#) to track key contributions and foster accountability
- Use a Brave Space Agreements or a process to co-create the ground rules and expectations for how members engage with each other

- Provide support throughout the Expert Advisory/Decision-Making Group (e.g. providing access to peer support/de-briefs)
- Handover processes to share information between the Expert Advisory/Decision-Making Group and project team

This can be developed into a Terms of Reference – this described in [our report](#).

Research Stage Four: Collect



Collect Research Life Cycle Stage: 4

Key Question:

How will Lived Experience values and methods inform how you collect the information to answer your research question?

Dr Cat Commentary



I did a randomised controlled trial for my Ph.D so that I could learn more about quantitative research because I did not see many people with Lived Experience in this space – I felt quantitative research was important to understand and transform. I think there are lots of people with Lived Experience who are drawn to technical roles like data analysis. Spread the word that we need them and they are welcome!!

The scoping review and interviews demonstrated that having Lived Experience people conduct data collection was important and feasible with the right training, mentoring and support (49). A study by Blueprint Writing (49) reported that young consumers were able to learn about research, be active co-researchers including in qualitative data collection (i.e. interviews), as did others (52). Reflective and development opportunities such as creating an active dialoguing between the researchers and Lived Experience co-researchers to reflect about their roles was important (53).

✓ **Action 13. Create a Lived Experience-centred data collection plan**

Collecting data is an important and distinct part of the research method, and it is a phase of the research process where people with Lived Experience are often left out (18, 54). Mixed methods research projects will use quantitative and qualitative data collection methods. Alternative methods of data collection (e.g. art, poetry, photo diaries) are also possible.

Collecting qualitative research

Qualitative methods are important for Lived Experience research because they give people a chance to share their experiences in their own words. This approach values personal narratives and encourages researchers to listen to what people with Lived Experience and the community want to express (55) in line with consumer values (44). Qualitative research gives people from the community a unique chance to share what is important to them, including the social issues that should be focussed on. This includes inductive methods that seeks to understand the subjective experience of participants without imposing categories or themes that have been pre-determined by the research team (56). Lived Experience people can lead and conduct various methods of qualitative data collection (interviews, focus groups, observation studies), these are detailed in [our report](#).

Collecting quantitative research

Quantitative research is important to understanding public health data and establishing the effectiveness of interventions (including medications and psychosocial interventions), it can be used to test if they are safe and should be used in public mental health services. Because of the way that quantitative research is conducted it can feel impersonal or objectifying – this is an exciting frontier for Lived Experience researchers to address (18). People with Lived Experience can lead and contribute to:

- The development of Lived Experience-centred surveys
- The delivery of surveys and data collection
- Working together to identify, understand and contextualise important quantitative service data, including that relating to consumer safety (e.g. data regarding the use of seclusion and restraint)
- Better understanding of how to collect public data

- Developing Lived Experience-centred quantitative measurement tools and methods

Quantitative research is essential to understanding research questions that cannot be addressed rigorously by qualitative methods (e.g. statistical measures of effective and risk of harm from interventions, longitudinal data, public data sets, etc.).

Workbook Exercise 13. Create a Lived Experience-centred data collection plan



Create a Lived Experience-centred data collection plan

Gather as a project team and explore the following questions:

1. What are five ways (or more!) that people with Lived Experience could be active members and leaders in this projects' data collection? What roles could they play in:
 - The development of data collection processes and data collection questions (e.g. for surveys, focus groups, etc.)
 - Lived Experience-led data collection and/or co-facilitation
 - Creative and unconventional forms of data collection (e.g. artwork, poetry, etc.)
2. What support, mentoring and training will be required so that the Lived Experience contributors/co-researchers can complete high quality data collection? For example:
 - Co-mentoring
 - Training
 - Skill share programs

Are there any more supports that your team would like to add?

Research Stage Five: Analyse



Analyse Research Life Cycle Stage: 5

Key Question:

How will you make sense of the information that you have collected and decide what it means? Who will be involved in checking that this interpretation reflects the perspectives of the research participants?

Dr Cat Commentary



I think lots of people have the aptitude to learn a range of research skills. For example, peer workers bring great engagement skills that can help us make sense of our data and develop great translational recommendations. Shifting our focus from requiring research qualifications to focusing on research skills echoes international trends reported in Harvard Business Review: <https://www.youtube.com/watch?v=P308O3U0gMM>

✓ **Action 14. Create a Lived Experience-centred data analysis plan**

Once your research data has been collected, you have to analyse the data and confirm that your interpretation is faithful to what your participants were expressing. This can be done through formal processes such as member checking, engaging your Expert Advisory/Decision Group or other Lived Experience experts (including peer workers) (54). Doing this through inclusive practices that are accessible and in line with cultural integrity and intersectionality is key. We note that every research project is unique and encourage you to work with people who have Lived Experience to develop the analysis method and ways of working together that are right for your research project.

Qualitative research

Understanding how qualitative research is done and analysed is crucial for building trust between researchers and people with Lived Experience. By valuing personal stories and actively engaging with people, researchers can conduct more inclusive and meaningful studies (44). Qualitative research is a valuable tool for both traditional researchers and Lived Experience experts to ensure consumer perspectives are heard in research. A research project can show that it is trustworthy through:

Member checking: When researchers ask participants to review the findings to ensure their voices are accurately represented.

Awareness of bias: Researchers should acknowledge their own biases to ensure the findings reflect participants' views rather than their own. A reflexivity statement which addresses the strengths and limitations of the Lived Experience within the research team can support this (see [Reporting Guidelines](#)).

Transparency: Check if the researchers discuss and report any ethical issues or problems that may have arisen.

Acknowledgments: Studies that value Lived Experience experts are recommended to report this in the acknowledgments section and in authorship.

Limitations section: A part of the paper or report that details on some of the limitations of the study including that relating to researcher bias or the lack of Lived Experience involvement in the research process.

Quantitative research

Quantitative data can be analysed through many different methods. This can feel intimidating at first, but we can demystify it by talking through the results together and exploring how the findings answer our research question – this is an important part of any research project. There are many opportunities to engage people with Lived Experience in quantitative data analysis (54, 57), including:

- Lived Experience data analysts/experts
- Collaborative meetings where the results are presented and explored by research team and people with Lived Experience
- Presenting the results and exploring them with the Expert Advisory/Decision-Making Group
- Creative means to explore how these numeric representations translate to real life (e.g. play, storyboard, models/prototype)
- Sense checking and contextualising activities (e.g. meeting with community leaders, Lived Experience peak bodies, etc.)

When quantitative research is done rigorously it can produce trustworthy and reproducible results that are also Lived Experience-centred.

Workbook Exercise 14. Create a Lived Experience-centred data analysis plan



Create a Lived Experience-centred data analysis plan

Gather as a project team and explore the following questions:

1. What are 5 ways (or more!) that people with Lived Experience could be active members of our data analysis? For example, what roles could they play in:
 - The development of data analysis processes
 - Data analysis, theming, contextualising the results
 - Validating that the results are interpreted in line with Lived Experience values and concepts (e.g. facilitating member checking and engagement with Lived Experience peak bodies)
 - Contextualising the results in light of what we know about people's real-life experience of distress, supporting others and using services
2. What support, mentoring and training will be required so that the Lived Experience contributors/co-researchers and broader project team can support data analysis? For example:
 - Reflective practices
 - Workshops
 - Community based activities (e.g. site visits, key stakeholder and community leader engagement, etc.)

Are there any more stages/tasks that your team would like to add?

Research Stage Six: Share



Share Research Life Cycle Stage: 6

Key Question:

How will you share the findings and recommendations from your research project with study participants, the community and other key stakeholders?

Dr Cat Commentary



During my PhD, I heard a Professor say “Research unpublished is research UN-DONE!” How we communicate about our research project is essential to rigorous research and is an important opportunity for us to demonstrate our understanding and respect for the people who are impacted by our research question.

Typically, reporting guidelines are not tailored for mental health Lived Experience-centred research and you must be careful when you use them so that you do not dehumanise or objectify people’s experiences. I use a combination of reporting frameworks with wholehearted Lived Experience writing which is values-driven, trauma-informed and Lived Experience-centred.

It is important to share your findings with your participants, funders and other key stakeholders throughout the project. This has traditionally taken the form of a written report, conferences and peer-reviewed journal articles. However, these are often not accessible to the community, and can be hard to read or make sense of. Dissemination is a key opportunity to have people with Lived Experience lead, contribute to and be active sharers of the research project’s findings. Lived Experience research team members and members of a Lived Experience Advisory/Decision Group can help identify messages and communication styles that are important to consumers, families, carers, supporters and kin. It is good to give Lived Experience contributors an indicator of how long this process could take – people are often very keen to see the impact of their contribution.

✓ **Action 15. Creating a Lived Experience-centred dissemination plan**

This should consider traditional and novel ways to share what you found. Video and multimedia content can increase accessibility. Plain Language Statements and writing in Easy English is recommended (58).

Workbook Exercise 15. Create a dissemination plan



Create a dissemination plan

Gather as a project team and consider the following questions:

Who will we share our findings with?

- ✓ The community (including First Nations and intersectional communities)
- ✓ Research participants
- ✓ Mental health service users and their families, carers, supporters and kin
- ✓ Lived Experience investigators and contributors
- ✓ Peer workers, other front-line workers, organisational and executive staff

How?

- ✓ Open access peer reviewed publication
- ✓ Written report
- ✓ Poster/multimedia/social media

When? Please describe

Are there any areas/stages that your team would like to add?

✓ **Action 16. Report your research project in a way that is Lived Experience-centred and rigorous**

This toolkit presented a Lived Experience-centred tool in [Table 1](#). This should be used alongside other reporting guidelines (18). Common reporting guidelines are available through Equator (<https://www.equator-network.org/reporting-guidelines/>) and includes:

- CONSORT – Randomised controlled trials
- PRISMA – Systematic reviews
- COREQ – Qualitative research
- GRIPP 2 – Consumer and public involvement in health research

Workbook Exercise 16. A plan to develop Lived Experience-centred reporting



A plan to develop Lived Experience-centred reporting

Gather as a project team and consider the following questions:

1. Which guidelines and standards should inform how your research team reports and communicates?
2. How will your research team tailor your reporting so that consumers and families, carers, supporters and kin feel respected, heard and valued? E.g. What are some of the terms, languages or concepts that should be used? And what are some of the terms, languages or concepts that should not be used?
3. What are three good examples that could guide your research team?

Are there any more questions that your team would like to add?

Chapter Four: Evaluating the Impact of Lived Experience-centred Research

Overview

This chapter presents processes and tools that can be used to evaluate if Lived Experience leadership, engagement and values have impacted the research project including:

- Why it is important to evaluate the impact of Lived Experience contributions throughout the research project

What are the key takeaways from this chapter?

Advocate – This chapter directly addresses moving beyond tokenistic involvement through accountability tools

Implement – This section provides two accountability tools that build on the *Actions* and workbook exercises from this toolkit

Evaluate – Evaluating the impact of Lived Experience in a research project is continual, essential and addresses every step of the research life cycle

Dr Cat Commentary



This section asks researchers to demonstrate where, when and how were people with Lived Experience were part of your research project? What did your research do differently in response to their input and leadership? Is your research project truly Lived Experience-centred.

Lived Experience literature has often cited that the inclusion of people with Lived Experience in the research process has been tokenistic or limited to being research participants (23, 59-61). This holds research teams to account for the level of Lived Experience input underpinning their project and the degree to which they have listened to and implemented this (62).

✓ **Action 17. Evaluate the impact of engaging people with Lived Experience as leaders/contributors in your research project**

The workbook exercise in Action 17 can be contextualised with other relevant government and Lived Experience guidelines. For example, in Victoria, the Mental Health Lived Engagement framework's (63) - we are purposeful; we are prepared; we are genuine; we are inclusive; and we communicate!

Workbook Exercise 17. Articulate how Lived Experience was integrated throughout your research project



Articulate how Lived Experience was integrated throughout your research project

Gather as a project team and consider how you track and evaluate the impact of Lived Experience contribution throughout your research project.

Complete [Table 4](#). This table is based on the [Actions](#) listed in the toolkit.

Table 4. Evaluating how Lived Experience was integrated throughout a research project

Research project stage	Lived Experience contributor/s (role)	Details of contribution (E.g. What, when, where, how)	What Lived Experience values, concepts and methods were used
STAGE ONE: CONNECT & IDENTIFY			
Action 1. Create a Lived Experience intention and impact statement			
Action 2. Harness community and industry relationships			
Action 3. Identify a research question and validate that your research question is important to your community			
Action 4. Form a Lived Experience-centred research team			
STAGE TWO: POWER & DECISION-MAKING			
Action 5. Embed Lived Experience and intersectional expertise throughout the project			
Action 6. Create a plan to ensure that your research project is accessible and inclusive			
Action 7. Create a Lived Experience-centred research culture and processes that unites the team			
Action 8. Create a plan to support the mental health and wellbeing of all members of the research team			
Action 9. Create a plan detailing how the research team shares power and makes decisions			
STAGE THREE: METHOD			
Action 10. Develop a research method that is rigorous and Lived Experience-centred			
Action 11. Explore Lived Experience and participatory research methods			
Action 12. Explore Expert Advisory and Decision-Making Groups, committees and governance groups			
STAGE FOUR: DATA COLLECTION			
Action 13. Create a Lived Experience-centred data collection plan			
STAGE FIVE: DATA ANALYSIS			
Action 14. Create a Lived Experience-centred data analysis plan			
STAGE SIX: SHARING			
Action 15. Creating a Lived Experience-centred dissemination plan			

Action 16. Report your research project in a way that is Lived Experience-centred and rigorous			
STAGE SEVEN: EVALUATION & IMPACT			
Action 17. Evaluate the impact of engaging people with Lived Experience as leaders and active contributors in your research project			

The Lived Experience Action Log is also an essential tool for demonstrating how Lived Experience expertise has been collected and used in a research project, it was presented in our section [Power](#). Here is an example of how the Working It Out Together team used this to track and evaluate our work and measure accountability.

Case Study 4. Working It Out Together project – Complete Lived Experience Action Log

Working It Out Together project – Lived Experience Action Log

In the project, we used a Lived Experience Action Log as an accountability tool. The first section (blue) was filled out as a part of our routine minute taking including actions, recommendations and reflections. This was filled out during the meeting. The second section (purple) is filled out after the meeting and is reported back to the team to show how their feedback was integrated. This was an important accountability tool for us and established transparent decision-making (see [Power](#)).

EAG	Actions, recommendations and reflections - summary	Person/Project team accountable	Action progress	Outcome – Part A	Outcome – Part B – Complete for items that were not actioned – state reason
EAG 3	Co-design/co-production and way of working together are important	Project Lead/Team	Partially addressed	Future treasures	This is introduced in the toolkit/report but worthy of a separate deep dive/tools
EAG 3	The importance of relationships in the research team and sharing/learning from each other in EAG	Project Lead/Team	In toolkit and report	Complete	
EAG 3	Negotiating what participants and researchers wanted from coproduction, what are the limits/boundaries/time/resources	Project Lead/Team	In toolkit and report	Complete	

Conclusion

Dr Cat Commentary



Thank-you for joining me on this Lived Experience research journey. I hope that the tools and resources that the Working It Out Together team and I developed have been a meaningful and helpful way to explore your project.

As you prepare for your next adventure take some time to reflect on the things you and your team learned by Working It Out Together!

I'd love to hear how about your journey – how did you customised the definitions, workbook exercises and explored additional information to work for your project. What lessons, workbook exercise or processes will you use again?

So, what will you do today to show people that we can change the lives of consumer, family/carers/supporters/kin and the community by working it out together?

Peace,

Dr Cat

Research Toolkits

Table 5. Research toolkits

Name	Author/s	Year	Research	Lived Experience	Intersectionality	Weblink
Safe research partnership with people with Lived and Living Experience: Reflective Guide for People with Lived and Living Experience Partnering in Research	Community Mental Health, Drug and Alcohol Research Network and Lived Experience Australia	2025	✓	✓	✗	https://cmhdaresearchnetwork.com.au/wp-content/uploads/2025/04/CMHDARN_LE-ReflectiveGuide-final.pdf
Safe research partnership with people with Lived and Living Experience: Checklist for researchers partnering with people with Lived and Living Experience (LE)	Community Mental Health, Drug and Alcohol Research Network and Lived Experience Australia	2025	✓	✓	✗	CMHDARN_LE-Checklist-final.pdf
Towards trauma-informed research: A brief overview and practice guide	Community Mental Health, drug and Alcohol Research Network and the University of Sydney	2024	✓	✓	✓	https://cmhdaresearchnetwork.com.au/wp-content/uploads/2024/07/CMHDARN_Towards_Trauma_Informed_Research_2024.pdf
Research essentials for the community sector	Community Mental Health, drug and Alcohol Research Network and the	2007, updated 2024	✓	✓	✓	https://cmhdaresearchnetwork.com.au/resource/research-essential-for-the-community-sector/

	University of Sydney					
Meaningful engagement of people with Lived Experience: A framework and assessment for measuring and increasing Lived Experience leadership across the spectrum of engagement	Ash, C., & Otiende, S.	2023	✓	✓	✓	https://nationalsurvivornetwork.org/wp-content/uploads/2023/01/2023-Meaningful-Engagement-of-People-With-Lived-Experience-Toolkit.pdf
Partnering with consumers standard	Australian Commission on Safety in Healthcare	2023	✗	✓	✗	https://www.safetyandquality.gov.au/standards/nsqhs-standards/partnering-consumers-standard
How ready, willing and able are you to embark on an authentic co-design process?	LELAN and the Australian Centre for Social Innovation	2023	✓	✓	✗	Resource Ready-Willing-and-Able-Co-design 2022-compressed.pdf
A toolkit to authentically embed Lived Experience governance	LELAN	2023	✓	✓	✓	https://nmhccf.org.au/our-work/discussion-papers/a-toolkit-to-authentically-embed-lived-experience-governance-centering-people-identity-and-human-rights-for-the-benefit-of-all
A toolkit for engaging young people with Lived Experience in the research that affects them	McCreary Centre Society	2023	✓	✓	✗	https://mcs.bc.ca/pdf/meaningfully_engaging_youth_lived_experience_toolkit.pdf

Leading the change: a Toolkit to evaluate lived experience inclusion and leadership	Mental Health Commission of New South Wales	2023	✓	✓	✓	https://www.nswmentalhealthcommission.com.au/leading-the-change
All of us: An introduction to our guide to engaging consumers, carers and communities across NSW Health	NSW Ministry of Health – Experience Team	2023	✗	✓	✗	https://www.health.nsw.gov.au/patients/experience/all-of-us/Publications/all-of-us-overview.pdf
Towards a meaningful evaluation framework for peer work: Short report 2023	Paino, E., et al.	2023	✓	✓	✗	https://opus.lib.uts.edu.au/handle/10453/172566
Engaging people with Lived Experience in research at University Health Network	PIPER	2023	✓	✓	✗	https://perc-phc.mcmaster.ca/app/uploads/2023/12/piper-tool.pdf
Diverse communities mental health and wellbeing framework and blueprint	Victorian Government	2023	✓	✓	✓	https://engage.vic.gov.au/project/diverse-communities-mental-health-and-wellbeing-framework/timeline/33531
Lived Experience principles checklist	VMIAC	2023	✗	✓	✗	https://www.vmiac.org.au/wp-content/uploads/LE-Principles-Checklist.pdf
Research participant checklist	VMIAC	2023	✓	✓	✗	https://www.vmiac.org.au/wp-content/uploads/Research-Participation-Checklist.pdf
VMIAC Lived-Experience-led research strategy 2023	VMIAC	2023	✓	✓	✗	https://www.vmiac.org.au/wp-content/uploads/VMIAC_Research-Strategy_2023-2026_FINAL_V1.pdf
WHO framework for meaningful engagement of people living with noncommunicable	World Health Organisation	2023	✓	✓	✓	https://iris.who.int/bitstream/handle/10665/367340/9789240073074-

diseases, and mental health and neurological conditions						eng.pdf?sequence=1
Co-production Kickstarter	Community Mental Health, drug and Alcohol Research Network	2022	✓	✓	✗	https://cmhdaresearchnetwork.com.au/resource/co-production-kickstarter/
Mind's participation and co-design practice framework	Mind Australia	2021	✓	✓	✗	https://www.mindaustalia.org.au/sites/default/files/2023-06/Participation_and_codesign_practice_framework.pdf
Engaging people with Lived Experience toolkit	Community Commons	2020	✓	✓	✓	https://www.communitycommons.org/collections/Engaging-Lived-Experience-Toolkit
The participation ladder: A consumer/survivor lens	Daya, I	2020	✓	✓	✓	Participation-ladder_consumer_survivor-lens-2.pdf
Framework for the engagement of people with a Lived Experience in program implementation and research	Suimo, Freeman & Banfield	2020	✓	✓	✗	https://www.blackdoginstitute.org.au/wp-content/uploads/2020/04/anu-lived-experience-framework.pdf
Co-production: Putting principles into practice in mental health contexts	Roper, C., Grey, F., & Cadogan, E.	2018	✗	✓	✗	https://healthsciences.unimelb.edu.au/_data/assets/pdf_file/0007/3392215/Co-production_putting-principles-into-practice.pdf

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Appendix

Design Expert Advisory Group and Expert Taskforce members

Design Expert Advisory Group (n = 23)

External Key Stakeholders: Dean Kolovos (Collaborative Centre); Rebecca Duke (Collaborative Centre); Dr Tessa Zirnsak (La Trobe University); Meghan Bourke (VMIAC); Amaya Alvarez (Tandem); Prof Chris Maylea (La Trobe University); Dr Peter McKenzie (Bouverie Centre – La Trobe University); A/Prof Melissa Petrakis (Monash University and St Vincent’s Hospital); Dr Justine Fletcher (University of Melbourne); Judith Wright (University of Melbourne); Puneet Sansanwal (University of Melbourne); Dr Marianne Wyder (Metro South Addiction and Mental Health Services); Prof Richard Gray (La Trobe University).

Wellways Australia members: Dr Catherine Brasier, Alec Scott; Caroline Lyall, Anita Conlon, Rowena Jonas, Jamie Lee Lalic, Jay Little, Jessica Schirmer, Charunda B. Bodaragama, Athena Field (NSW ACT QLD Practice Lead, Peer Support), Robert Trewin (La Trobe University student), Clare Joseph (La Trobe University student).

Expert Taskforce members: VMIAC community members (n = 8), Tandem community members (n = 8), ALIVE Governance members, Cath Roper (University of Melbourne), Flick Grey (Lived Experience consultant), Emma Cadogan (Lived Experience Policy, Lived Experience Branch – the Victorian Department of Health), Kayla Robertson (Lived - Participant and Family Engagement Practitioner – Wellways Australia), Violeta Peterson (Director of Carer Lived and Living Experience – The Alfred Hospital), Rebecca Langman (Director of Lived Experience – The Alfred Hospital), Prof Lisa Brophy (Social Work and Social Policy, La Trobe University), A/Prof Bridget Hamilton (Director of Centre for Mental Health Nursing – University of Melbourne), Rene Puckeridge (Peer Workforce Leader – Stride), Catherine O’Donnell (Director Lived Experience Engagement and Co-Lead Mind Labs – Mind Gardens)



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