The Victorian Collaborative Centre
For Mental Health & Wellbeing

Working it out together

Phase 2 Report

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

wellways

LA TROBE UNIVERSITY

VICTORIA State Government

Preface

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

Collaborative Centre team: Dean Kolovos, Alicia Baker, Rebecca Duke, Katie Jones and the Collaborative Centre team.

Project Lead: Dr Catherine Brasier – National Manager of Evaluation and Research (Lived Experience) and Adjunct Research Fellow, School of Social Work and Social Policy, La Trobe University.

Wellways Australia project team: Alec Scott - Lived Experience Research Assistant; Caroline Lyall - Lived Experience Research Assistant; Anita Conlon - Lived Experience Co-production and Engagement Lead; Rowena Jonas - Practice Advisor Families and Carers; Jamie Lee Lalic - Reconciliation Action Plan Officer; Jay Little - After Suicide Support Worker; Jessica Schirmer - Policy Advisor; Charunda B. Bodaragama - Implementation Lead; Robert Trewin - Bachelor of Social Work (Honours), student placement, School of Allied Health, Human Services and Sport, La Trobe University, Shepparton; Clare Joseph - Master of Social Work Student, student placement, School of Allied Health, Human Services and Sport, La Trobe University, Melbourne.

Qualitative Lead and Senior Lived Experience Collaborator: Dr Tessa Zirnsak, Research Fellow, Department of Community and Clinical Health, La Trobe University.

Guest contributor for Chapter One: Simon Katterl – Simon Katterl Consulting

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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 to 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.

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 and report 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: The toolkit and report 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, families, carers, supporters and 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).

Report we cover:

- **The critical value of Lived Experience-centred research.** An introduction to the pivotal and life-changing impact of engaging people with Lived Experience as the leaders and creators of research.
- **Implementing Lived Experience-centred research.** This chapter explores how to integrate Lived Experience throughout the research life cycle to "work it out together":

- **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: This project drew on a vast range of research and engagement skills, techniques and expertise. The project demonstrates that "working it out together" is the key to success. It demonstrated 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. We noted that the success of 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

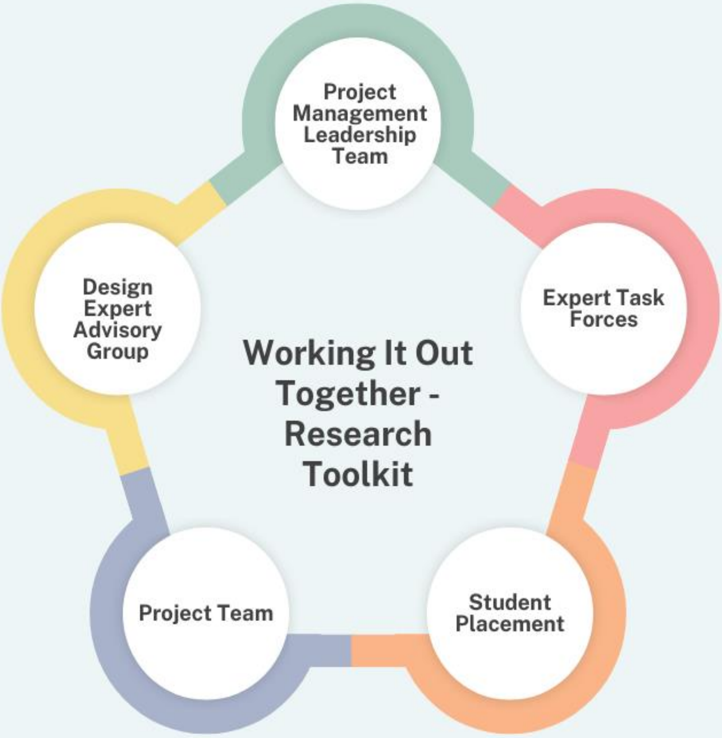
The purpose of this report is to foster Lived Experience-centred research that responds to the needs, priorities and experiences of people who use mental health services. The “Working it Out Together” project team took a “walk the walk” approach to this project. We have included case studies and tools based on this project throughout the workbook – see Case Study 1 below:

Case Study 1. Working It Out Together project - Case Study

Working it Out Together project - Case Study

We used a method that combined traditional research methods with Lived Experience-centred design and product development. This project was Lived Experience-led and included Lived Experience leadership from the Collaborative Centre, Wellways Australia and La Trobe University. It included people working from designated consumer, carer and intersectional perspectives.

Working It Out Together - Project structure



Our method

We validated our findings by engaging people with Lived Experience, research and service delivery/design experience throughout the project using Lived Experience-centred methods. For example, we:

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).

Working it out together was central to our success. Feedback from our team, the Design Expert Advisory Group Members and Expert Taskforce members reflected that this was a mutually beneficial process that the team.

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Chapter 1 - Advocacy, literacy, and articulating the value of working together

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.

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

The importance of working with Lived Experience to create life changing research

In Australia and internationally, mental health consumers, families, carers, supporters and kin play little to no role in most mental health research and this contributes to poor outcomes and experiences. Peer reviewed literature and health policy has been advocating for people with Lived Experience to be active leaders and producers of research for more than 20 years, but there has been little change in mainstream practices [1-3].A Lived Experience-led rapid scoping review conducted by Wellways in 2023 for the Victorian Collaborative Centre for Mental Health and Wellbeing identified 81 peer reviewed and grey literature publications, and consulted with 23 people [4]. Publications included Lived Experience-led and non-Lived Experience-led literature. Consultations included eight consumers, three carer, family and supporters, five consumer leaders, three carer, family, supporter leaders, one First Nations carer, and three research and senior service delivery allies).

The review and consultations confirmed that the people most impacted by mental health research and evaluation are often left out of the research process. People with Lived Experience were not involved in defining the research problem and often do not find out the outcome of the evaluation or research. People with Lived Experience (including peer workers) are often left out of technical activities such as design, data collection and analysis but could become more involved in these tasks through capability building, training and education, mentoring and opportunities to build these skills on the job. Support and mentoring for people with Lived Experience who choose to undertake formal research pathways are also key. Mainstream mental health researchers in universities and health services will need Lived Experience values-based support to become impactful and innovative researchers and allies.

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 pursuit of 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 as researchers and the academy have failed to recognise how their power and privileged has shaped outcomes [5]. This research has often been stigmatising and fails to address the questions that people with Lived Experience care about the most. Research and evaluation are powerful tools to help challenge our institutions, including within academia itself, and are a natural 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.

Summary of recent policies which impact on Lived Experience and research

Lived Experience participation and leadership has been encouraged by International and Australian policies for many years but is yet to be routinely implemented [6, 7]. Until recently Australian mental health policy has almost exclusively focused of the provision of mental health services [8]. Increasingly, policy documents refer to the importance of Lived Experience in developing policy and services, although this is often vaguely reported or done by consultations and may be tokenistic; this is a lost opportunity as it fails to recognise how the leadership of consumers, families, carers, supporters and kin and ensure that the policy reflects their experience. There are few formal accountability structures to measure, monitor and adhere to these commitments.

The 'Fifth National Mental Health and Suicide Prevention Plan' noted that there was a significant disconnection between research and the mental health sector [1]. It recommends the National Mental Health Commission work with the National Health and Medical Research Council (NHMRC), mental health consumers and families, carers, supporters and kin, and other key stakeholders (e.g. states and territories, research funding bodies and prominent researchers) to develop a research strategy that improves outcomes [1]. This plan acknowledges the contributions of people with Lived Experience and Aboriginal and Torres Strait Islanders through a consultation process and reports that consumers and families, carers, supporters and kin should be partnered with in the planning and decision making.

The Productivity Commission's 'Inquiry into Mental Health' [8] concurs and states that the Australian, state and territory governments should agree on a set of targets and timeframes that specify key mental health and suicide prevention outcomes. The Productivity Commission stated that these targets should be co-designed with consumers and families, carers, supporters and kin and include both quantitative and qualitative evidence and data. Further, it recommended that Aboriginal and Torres Strait Islander people and the National Federation Reform Council Indigenous Affairs Taskforce should be included in discussions about any targets that may affect Aboriginal and Torres Strait Islander people (Action 24.4) [8]. This includes considerations around quantitative and longitudinal research. The Commission suggested eight principles: That research is:

1. Fit for purpose
2. Maintains social licence
3. Supports continuous improvement
4. Independent
5. Transparent
6. Person centred
7. Cultural integrity
8. Generates a net value

Summary of government policies addressing partnering with consumers

Both international and Australian [3] health policies are increasingly stating that they want to partner with consumers families, carers, supporters and kin to deliver services. There is also increased emphasis on creating systems that are designed and used to support health consumers and families, carers, supporters and kin to be partners in healthcare planning, design, measurement and evaluation; the Partnering with Consumers Standard (Standard 2) outlines the importance and benefits of partnering with consumers [9], this includes measuring consumer experience and the use of self-reported measures instead of clinician reported measures. The Mental Health and Wellbeing Act 2022 (VIC) objectives state the importance of centring the experience of consumers (and families, carers, supporters and kin) in changes of practice, service design, delivery, and evaluation [10]. The Victorian Government's Mental Health Lived Experience Engagement Framework [11] guides policy makers to engage more meaningfully with people who have experienced mental or emotional distress and their families, carers, supporters and kin.

Our Lived Experience history – the journey of mental health consumers and families, carers, supporters and kin

Reflecting international trends, Australia has a growing interest in involving mental health consumers and families, carers, supporters and kin [12-14]. This includes Lived Experience-led research [15-17]. However, this is complicated by social and cultural factors such as the history of disempowering consumers and families, carers, supporters and kin through systemic approaches such as institutalisation and coercive practices, and in contemporary practice through the on-going legacy of low expectations about the future of people who have serious and on-going experiences of distress [18]. In Victoria, the Lunacy Act governed our mental health system for 100 years and was most notable for its use of asylums as a principal response to distress. People who experienced the asylums as 'patients' or workers are still living members of our community in Victoria. The use of mental health asylums was discontinued because of the 1986 Victorian Mental Health Act [19], and the subsequent 2014 Victorian Mental Health Act [20] laid the groundwork for a community-based mental health system. Despite this, a lack of community support, stigmatising representations of mental distress perpetuated long held cultural beliefs that people experiencing distress are powerless, unwanted and potentially dangerous. These features reflect a system that was not designed by, or in partnership with, the people who use it.

The contemporary Lived Experience Movement began in the 1970s-1990s in response to the "patient" or "survivor" movements in the UK and US, and later influenced the Australian Lived Experience movement [15]. Core to this was challenging the authority of the medical model of mental health which assumes that it is the persons' deviation from normal biological functioning that is the cause of the illness [2, 21]. During this period psychiatrists and clinicians were seen as the experts, not consumers or families, carers, supporters and kin. Consumer leaders also highlighted the lack of community supports available to people once the asylums closed [22, 23]. More recently there has been the introduction of Mad Studies, including international journals emerging from Australia [24]. This discipline emerges from the Mad Community and seeks to challenge power structures inside and outside "the academy" (academic and formal knowledge-making institutions) [25], as well as providing a venue for mad-led knowledge to be shared [24].

Contemporary approaches to mental health and wellbeing propose that mental distress is a response to complex social factors, often referred to as the social determinants of mental health [26]. Social determinants such as socio-economic status/class, education, marginalisation, social disconnection, impacts of colonisation and intergenerational trauma, housing insecurity recontextualise mental health as a social issue, as opposed to a personal failing or illness. This also highlights how consumers and their families experience powerlessness due to systemic factors and cultural issues such as stigma. Mental health literature, especially that which is consumer or carer-led, promotes recovery as an ongoing, non-linear journey and the possibility that people who experience even intense or on-going challenges can also lead happy and successful lives (with or without "symptoms") [27].

The Royal Commission intentionally sought feedback and suggestions about people's experiences with our Mental Health System, and collected an unprecedented level of consumer, carer and community feedback [18]. Many of the witness statements described challenges including accessibility, inadequate or unhelpful experiences, widespread coercive and restrictive practices. The Royal Commission recommendations were accepted in full by the Victorian State Government and 2022 the Mental Health and Wellbeing Act (Recommendation 42 of the Royal Commission) 2022 (VIC) was passed to support the reform [28].

Understanding the experiences and history of mental health consumers

Australian mental health consumers are a diverse community who each experience unique challenges connected to their psychosocial health [29]. This includes mental health consumers who experience significant mental distress and may use acute and complex mental health services. It also includes people who have more common experiences, such as anxiety and depression, and those who use private and primary mental health supports [8]. People with Lived Experience also come with intersectional identities that are impacted by privilege and oppression, including based on gender, disability, race, and whether they are Aboriginal and/or Torres Strait Islanders.

The Royal Commission documents both how consumers can be harmed by mental health practices (e.g. through the violation of human rights such as compulsory treatment including seclusion or restraint, and coercive practices like Compulsory Treatment Orders), and the failure to receive life changing support [30-32]. The Royal Commission acknowledged that consumers have been marginalised by a ‘broken’ mental health system and often experience high levels of marginalisation, unemployment, poverty, homelessness and isolation [18]. Many consumers identify that they often cannot access services when they need them, but they continue to be left out of system design, research and evaluation. Victoria also has a growing Lived Experience and peer workforce who use their Lived Experience in combination with professional skills to support others and be an agent of systemic change [33]. The Royal Commission found there are complex power imbalances that come from professional, historical, social and statutory hierarchies that continue to impact consumer, family, carer ,supporter and kin involvement [10].

This may be due to several factors such as disruptions to education, feeling like they do not belong in research environments [17], or because researchers do not identify as Lived Experience or work from that perspective. People working within universities and professional settings can feel discouraged from sharing that they have a Lived Experience [34].

Understanding mental health families, carers, supporters and kin

Families, carers, supporters and kin contribute billions of dollars in unpaid work to the Australian economy [35] and often experience poorer health outcomes. Australia's National Carer Wellbeing Survey 2022 indicated that mental health families, carers, supporters and kin have poorer outcomes than other carers, and they report being impacted by stigma [36]. Since the deinstitutionalisation of the Victorian Mental Health System families, carers, supporters and kin report that they have not been adequately supported to provide care, receiving little support, education or resourcing to do the work [18]. When families, carers, supporters and kin get the right support early and continuously, the benefits flow through to the people they support, their wider family and their communities. Many families, carers, supporters and kin strongly feel that recovery from significant mental distress happens through relationships. Innovative research in the carer, family and supporter space has shown that recovery processes are not static and individual family members can be at different stages [37].

Since the Royal Commission into Vicotria's Mental Health System (hereafter, the Royal Commission) [18], the Victorian State Government has increased the involvement of families, carers, supporters and kin within mental health system reform to drive change, although this is still insufficient compared to what is needed to make significant change. The family carer workforce is undergoing rapid change and has typically been an underdeveloped and underutilised part of the peer workforce, often receiving less FTE workforce [33, 38]. The carer, family and supporter workforce need assistance to find solutions to support families better and to facilitate meaningful change across the sector.

First Nations people and communities and mental health research

The 'Fifth National Mental Health and Suicide Prevention Plan' reports that suicide rates for Aboriginal and Torres Strait Islander people are twice as high as those for non-Indigenous Australians [1]. This has been linked to stressors such as discrimination, racism and social exclusion, intergenerational trauma, grief and loss, removal of children, economic and social disadvantage, family and community violence, incarceration, substance use and physical health problems [1]. Despite this First Nations people often lack representation in research and service development and delivery. Non-government organisations such as Wellways have led the way by implementing First Nations specific innovations such as a dedicated Reconciliation Action Plan Officer who leads the organisation's First Nations Caucus and First Nations Retreat.

Embracing intersectionality – the power of diverse voices in research

People from diverse backgrounds are often underrepresented in mental health research and service design and delivery [8]. In this report when we refer to diverse backgrounds we are referring to people from culturally and linguistically diverse communities, Lesbian, Gay, Bisexual, Transgender, Intersex, Queer, Asexual, Sistergirl, Brotherboy (LGBTIQ+SB) people and people with disability, as well as young people and older people. Victoria's 'Diverse Communities Mental Health and Wellbeing Framework and Blueprint' [39] highlights that people from diverse communities may:

- Experience discrimination and stigma related to mental distress as well as their diverse backgrounds, identities and attributes
- Sometimes mental health supports are difficult to find out about or access
- Experience mental health services that might not be safe, inclusive or responsive to their needs
- Have unequal access to the things that keep them from becoming distressed in the first place

Mental health researchers and academic pathways

In Australia in 2021, 5.5 million people reported having a Bachelor's degree or higher; this is a 30.7% increase from 2016 [40]. Since the year 2000, the PhD graduation rate has increased from 1.3% (under 4000 people) to 2% (around 10,000 people) of all graduations in 2012 [41]. PhD students face many challenges such as competing demands on their time, family issues, financial pressures, inadequate support and insufficient orientation from universities [42]. Only a small number of those who complete a PhD manage find a postdoctoral research fellowship position. This is partly because the number of PhD students have been increasing in Australia and because postdoctoral positions are highly competitive. Post-doctoral positions are considered a required step in a professional academic career.

Once in academia, researchers face many challenges. There is a ‘publish or perish’ culture whereby academic publishing and research are a crucial part of the pathway to on-going employment. Other reported barriers included being female and the hierarchical culture [43]. Obstacles faced by researchers include the requirement to balance research with teaching commitments, job insecurity (e.g. causal and short contract roles, industry pressures) and the need to remain competitive by gaining grants and fellowships [43]. As a result, it has been found that academics experience lower levels of wellbeing and higher levels of burnout and mental distress compared to the general population [44].

Case Study 2. How we are hoping to change mental health and wellbeing research by 'walking the walk'

How we are hoping to change mental health and wellbeing research by 'walking the walk'

The "Working It Out Together" project emphasised the importance of "walking the walk", to the extent that it was possible we conducted this translational project in the same way that we advise in our report and toolkit. As we go through the report and toolkit, we will show how we approached different stages of the research project through a series of case studies based on our work.

Design Expert Advisory Group meeting 1- Validating our Working It Out Together research question: we completed a story board exercise that gave us a real-life chance to experience working together to find a common ground. The group reported that they often perceived academia and research as an institution made up of pillars (i.e. peer reviewed publications, Human Research Ethics Committees, institutions and practice) which can be oppressive, not Lived Experience-centred and unhelpful. It was noted that research principles and the research question are usually not set by consumers, families, carers, supporters and kin but are driven by external forces (e.g. media, government, economics imperatives, etc) that researchers must respond to. As a result, Lived Experience engagement in research can be experienced as tokenistic, as having implicit requirements (e.g. don't rock the boat), that people with Lived Experience are involved late in the game and may experience beliefs that are paternalistic or assume that they lack capabilities. Teams reported that research methods need to be more Lived Experience-centred, co-developed and conducted in a way that builds capacity in people who are working from a Lived Experience perspective. Finally, the storyboards highlighted that people with Lived Experience and the community do not have access to the information or findings that are generated through mental health research.

Design Expert Advisory Group meeting 2 – Developing our ideas about what the toolkit should provide: The group exercises gave the Design Expert Advisory Group members further experience in working across Lived Experience, research and service delivery/development. The groups had a chance to explore what it is like to intentionally discuss power sharing and how to work as a collaborative team before beginning the main co-production exercise.

The prototypes developed in the small group exercise emphasised the need to address practical elements (e.g. capability building, reflective and real-world examples), developing principles for working together and connecting as a team, as well as creating a shared language/understanding. The members felt it was important that research teams explored the expertise required to answer the research question, gain clarity regarding power, roles, responsibilities and expectations within the research team and the importance of exploring the strengths of both Lived Experience and non- Lived Experience team members. Teams also reported that mental health researchers need capability building to work effectively and safely with people who have Lived Experience and flexible methods which are adaptable and rigorous.

Design Expert Advisory Group meeting 3 – Feedback and development of the toolkit – This full day workshop aimed to test the ideas and tools developed so far. It included group reflections and exercises addressing what we felt "worked well for us" and "worked well for others", accessibility and inclusion, what made the group feel safe and work well. Overall, the Design Expert Advisory Group expressed a high level of satisfaction with their experience and provided constructive feedback about the toolkit examples.

Power sharing and decision-making – being accountable for how the Design Expert Advisory Group advice was used – At the end of each Expert Advisory Group the group was emailed a summary of the findings and the Lived Experience Action Log. The final Action log was share with them after the final Design Expert Advisory Group meeting.

Chapter 2 – Implementation of exemplary practice Lived Experience research

Overview

This chapter provides information to support researchers to design and conduct Lived Experience-centred research.

- Wellways "Six Steps of the Research Life Cycle" and a summary of the key Actions for each step
- How to connect to the people who can help you identify your research question
- Addressing power and decision-making
- Creating a Lived Experience-centred method
- How people with Lived Experience can support 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 on-going process of sharing the research projects findings

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 different ways

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

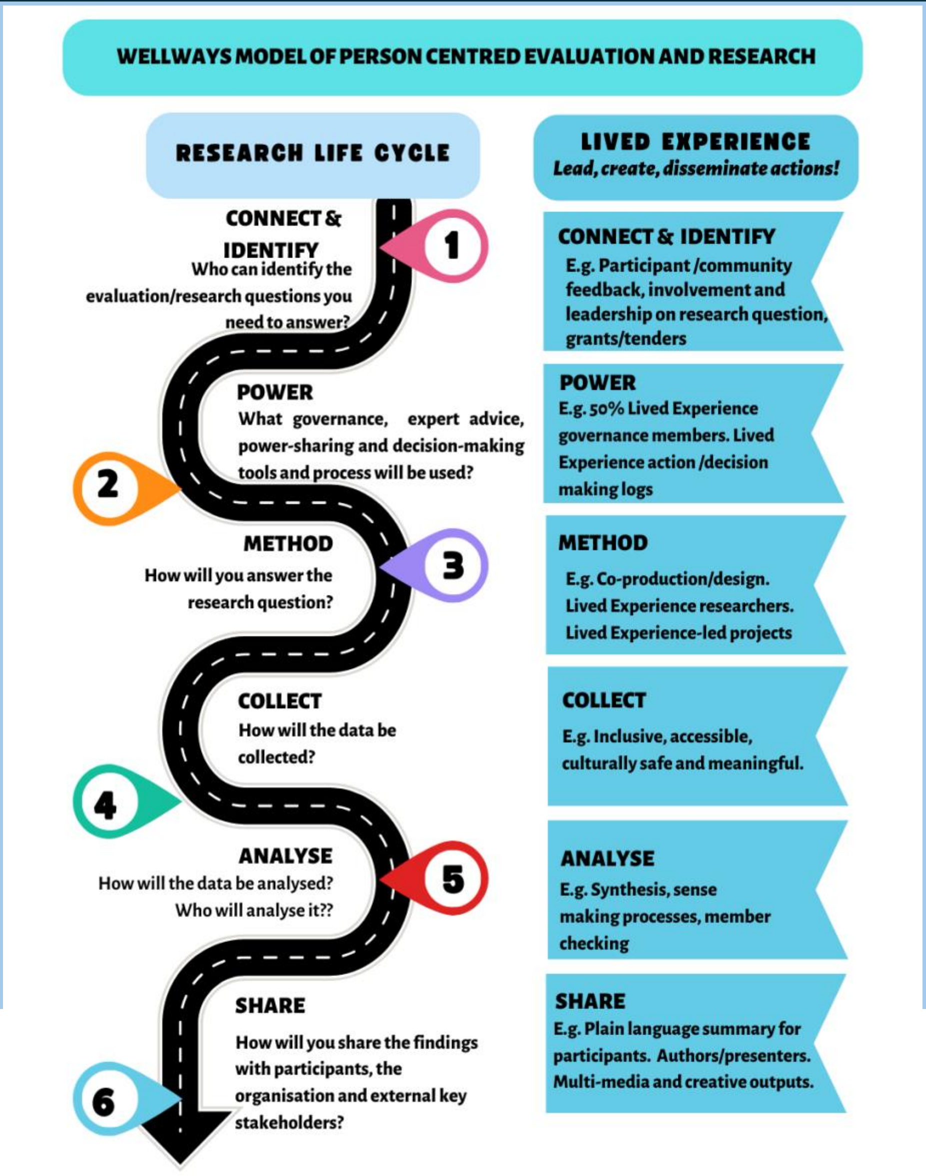
This chapter explores how translational Lived Experience research can be put into practice. It is based on Wellways' "Six Steps of the Research Life Cycle" which was developed by Dr Catherine Brasier and based on a scoping review which explored how people with Lived Experience could lead, create and disseminate research [45].

Wellways "Six Steps of the Research Life Cycle"

This model is based on our scoping review [4] that identified a number of core stages. It echoes previous guidelines and frameworks [46-48] and is presented in Figure 1:

Figure 1. Wellways "Six Steps of the Research Life Cycle"

Wellways six steps of the research life cycle



WELLWAYS MODEL OF PERSON CENTRED EVALUATION AND RESEARCH

RESEARCH LIFE CYCLE

LIVED EXPERIENCE
Lead, create, disseminate actions!

1 CONNECT & IDENTIFY
Who can identify the evaluation/research questions you need to answer?

CONNECT & IDENTIFY
E.g. Participant /community feedback, involvement and leadership on research question, grants/tenders

2 POWER
What governance, expert advice, power-sharing and decision-making tools and process will be used?

POWER
E.g. 50% Lived Experience governance members. Lived Experience action /decision making logs

3 METHOD
How will you answer the research question?

METHOD
E.g. Co-production/design. Lived Experience researchers. Lived Experience-led projects

4 COLLECT
How will the data be collected?

COLLECT
E.g. Inclusive, accessible, culturally safe and meaningful.

5 ANALYSE
How will the data be analysed? Who will analyse it??

ANALYSE
E.g. Synthesis, sense making processes, member checking

6 SHARE
How will you share the findings with participants, the organisation and external key stakeholders?

SHARE
E.g. Plain language summary for participants. Authors/presenters. Multi-media and creative outputs.

Working It Out Together research action list

This action builds 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

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?

This Research Life Cycle Stage includes a discussion of:

- Learnings for the scoping review
- The importance of how we come together
- Connecting with people who can help you solve the research problem

Learnings from the scoping review

In our scoping review, we found that the way that research projects identified and invited people with Lived Experience into a research study is crucial. Not having established good rapport beforehand, having thought of appropriate questions or taking the time to explain what people need to do was identified as a barrier to participation. Building relationships with families, carers, supporters and kin from the beginning and making sure they are aware why they are involved and what they can offer was also reported. It is also important to tell the community what your plans are and what you hope to get from it; and then allow them time to process their emotions and decide if they want to participate. First Nations people want to be heard and consulted with about what they need. Getting to know the local land councils and Aboriginal medical services is important to help understand what the community is going through and needs. To facilitate good and active involvement it is important to connect with Peak Bodies and other key partners. When connecting, it is important to be clear and transparent in acknowledging power differentials between all members of the research team.

Our scoping review identified barriers to people with Lived Experience leading, creating and sharing research such as lack of research skills/qualifications, being treated as a "service user", feeling unsafe, stigma and low expectations, not included in authorship or dissemination, too little influence, tokenistic involvement, conflicting perspectives, research industry demands (e.g. high pressure, intense workload, competitive), difficulty getting ethics committee approval, lack of input in ethics applications, and not being included at all stage of the research process (e.g. research problem definition, grant application, data collection, data analysis, dissemination). Research culture was a barrier because researchers often work separately from each other, missing opportunities for collaboration.

In Victoria, the Centre for Mental Health Nursing at the University of Melbourne runs a Consumer Academic Program which specialises in consumer-led and interdisciplinary research and educational projects. It seeks to co-create system and practice change with people with Lived Experience of mental health service use their families, carers, supporters and kin, and other professions. Underpinning this work are principles of enhancing practice of mental health nursing, translational research into mental health care and nursing, and advocacy for the voices of nurses and people with Lived Experience [33, 38].

The importance of how we come together

The Commission [18] and the Productivity Commission's Inquiry into Mental Health [8] stated that people with Lived Experience should be at the heart of the mental heart system, including leadership and governance. The Royal Commission used a range of feedback methods (written submissions, town hall meetings, etc.) to collect an unprecedented level of consumer, carer and community feedback so that we could solve these important problems together [18]. Many of the witness statements described inadequate or unhelpful experiences with the mental health system that gave important insights into the problem which had not previously been inquired into from a Lived Experience perspective. For many people with Lived Experience there was a recognition that this was the first time that they had really been asked about their experiences and treated as an important part of the solutions. The Royal Commission is an excellent example of how people with Lived Experience and other key stakeholders can come together using robust methods to define a problem, methodically collect information and solve problems together; this should set the bar for contemporary mental health research.

Case Study 3. A reflection on the international trends – By Dr Tessa Zirnsak (Qualitative Lead)

A reflection on the international trends – By Dr Tessa Zirnsak (Qualitative Lead)
The McPin Foundation in London is set up to improved Lived Experience engagement in mental health research. In July 2024, I visited to learn about what the foundation is doing and share information about Lived Experience in Australia. Many of the problems facing Australia researchers (e.g. lack of funding, precarious employment of Lived Experience researchers, and power resting with "traditional" researchers are being faced by staff at McPin and their networks. Regardless, the McPin Foundation have an established based of Lived Experience scholars who are strongly committed to developing leadership opportunities for others like them through the development of the Lived Experience community. These researchers are often employed across several projects and typically have research assistants or early career research roles – indicating that there is an international need for pathways for Lived Experience researchers to grow their academic track records and being taken seriously.

Despite on-going calls for people with Lived Experience to lead and participate in research, Lived Experience-driven research is still emerging [49]. Even though recent years have seen the rise of the Lived Experience and peer work movement, most mental health research relegates consumers and families, carers, supporters and kin to being research participants, not the creators or leaders of research [50, 51]. Recent research trends have advocated for more Lived Experience-centred participatory methods (e.g. co-design and co-production), although there is often a disconnection between these aspirations and how research projects are conducted [52].

Connecting with the people who can help you to identify and solve the research question

People with Lived Experience are often not involved in mental health research as active collaborators (i.e. as more than a study participant/data point). People with Lived Experience are often bought in to a research study after the research problem has been defined or after grants or funding has been awarded. Researchers who are interested in working with people who have Lived Experience can be unsure about when and how to promote Lived Experience leadership and collaboration in their research, this leads to many missed opportunities. We have addressed some suggestions for how people with Lived Experience (including those with intersectional perspectives) can be involved and lead research.

Forming a research team

Forming a research team should consider all of the people who can help research teams identify and answer their research questions. Below is a brief introduction to how researcher teams are often organised, it introduces terms such as “Chief Investigator” and other terms that are key to understanding the way research teams are structured in research grants, this is detailed in Table 1.

Table 1. Who is in a research team?

Where?	What is this?	How could Lived Experience lead, collaborate or contribute?	Doing things together would look like?
Investigator team: The investigator team is the research team members that the grant/project has been awarded.	Research project lead is the person who takes overall responsibility for the project including the budget, the rigorous conduct of the study and is responsible for ethics review and standards as determined by the Human Research Ethics Committee and study/trial registration. They are also responsible for the communication with the other study investigators. In research this position is usually held by one person. In studies where there is only one study site they may be referred to as the Principal Investigator (PI) or if it is a multisite study they may be called a	There is typically a specific criterion for being a Coordinating Principal Investigator or a Principal Investigator on a grant. This can include having completed a PhD and a "proven track record" of completed projects, publications and conference presentations. This can make it difficult for Lived Experience researchers/collaborators to lead competitive grants and determine the evidence as the Lived Experience academic workforce grows we should expect to see an increasing number of Lived Experience Coordinating Principal Investigators/Principal Investigators. Some Lived Experience	• A Lived Experience Coordinating Principal Investigator/Principal Investigator (Lived Experience-led) • Coordinating Principal Investigator/Principal Investigator working in collaboration with people on a grassroots/Peak Body level to conduct Lived Experience driven work and integrating them throughout the research project, especially in decision making roles • Projects including people with Lived Experience as the Coordinating Principal Investigator and Principal Investigators to build their track record • Advocating for more inclusive and experience-based criteria

	Coordinating Principal Investigator (CPI).	academics have led the way as project leads.	
	Investigator/s are the other named researchers on a grant who are responsible for managing the project, completing tasks and contributing to the project. This may include Chief Investigators who typically have significant research experience, publications or qualifications. This may include Associate Investigators (AI) who have more junior experience or research qualifications.	There are strict rules for who can be a Chief Investigator or an Associate Investigator; these rules differ between grants. To be eligible to be an investigator there are usually requirements around the level of research qualification and experience. There are some signs that people with Lived Experience (but without research qualifications) may be more recognised in the future.	• Having investigators that are working from a Lived Experience perspective
Research team	A research team includes a range of other researchers, experts and contributors who are employed to conduct, manage and contribute to the research project. This may include research assistants, data analysts and product designers.	There are many roles that people with Lived Experience can play within the research team. Roles may have varying requirements for formal research training (from novice to Lived Experience academic).	• Utilise Lived Experience academics/researchers in a range of roles • Aim for a critical mass of Lived Experience in the research team; at least (e.g. at least 50% of the research team as Lived Experience • There is good evidence to suggest that people can learn to complete many research jobs through mentoring and

			on the job training including data collection and qualitative data analysis
Expert Advisory Group/s	These groups are a formal part of a research project and can provide a range of input (ranging from feedback/consultation through to decision making) depending on the study requirements/design. The groups may include consumers, families, carers, supporters and kin, researchers, service staff, intersectional members and other key stakeholders). This should be a remunerated role and should be Chaired by at least one person with Lived Experience.	Unlike the investigator team and research team, Expert Advisory Groups are not required but they are strongly recommended. Expert Advisory Groups (including Consumer, Carer Advisory Groups and Diversity and Inclusion Groups) are becoming a standard expectation.	• Appoint at least one Lived Experience Chair or one Consumer Chair and one Carer Chair for combined groups

Research grants remain prescriptive about the experience and qualifications required by researchers to hold positions on a grant. This means that individual researchers may not be able to integrate Lived Experience throughout the study in the way that they would prefer. This can be frustrating for researchers as well as people with Lived Experience. There are some signs that major national funders (NHMRC and ARC) are rethinking these requirements, this is an excellent area for advocacy.

Case Study 5. A reflection on the international trends – By Dr Tessa Zirnsak (Qualitative Lead)

A reflection on the international trends – By Dr Tessa Zirnsak (Qualitative Lead)
Lived Experience expert Lisa Morrison, based in Belfast, has substantial experience working as a consultant to research. In July, 2024 I had an opportunity to meet with Lisa and hear about her experiences. Lisa explained that as a consultant on research projects, she is often beholden to the values and intentions of non-Lived Experience leaders. However, Lisa's experience of this was not all bad. She expressed that when she is working for some researchers – particularly those well and has worked with before – she knows that her voice will be take seriously and considered during decision-making. Of course, it takes time to develop this relationship with researchers, and to work out which one's are going to listen to Lived Experience.

Power and decision-making

Power
Research Life Cycle Stage: 2

Key Question:
How governance, expert advice, power-sharing and decision-making tools and processes will be used?

This Research Life Cycle Stage includes a discussion of:

- Intersectionality
- How experiences of distress and caring intersect with other forms of intersectionality
- First Nations people and communities
- First Nations and intersectionality
- The journey to allyship and partnership

Learnings from the scoping review

The Lived Experience community has often felt that their inclusion in research is token or that they lack the power to see their expertise incorporated. Systemic issues mean that many people with Lived Experience are excluded from leading grants and may feel "overruled", ignored or misunderstood. 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) in the research project. Co-produced research helps us to move from 'expert' and 'power over' to a more 'partnership' and 'ownership' dynamic. There is a need to be clear and transparent, acknowledging power between all members of the research team. There ought to be an acknowledgement of the impact of current and historical power differentials and how they impact the discourse and power sharing [53-59]. Moving forward researchers should make the research process accessible and inviting to the community. It is important to create a culture of equal and shared knowledge across all stakeholder groups [57]. People with Lived Experience need to have full authority, not just tokenistic consultation. There need to be an awareness of researchers or outsiders outnumbering people with Lived Experience in numbers, power, or influence [60].

Intersectionality

In our scoping review we found that intersectionality was mentioned as a key priority. Despite this information about how to incorporate it into research was difficult to find, and we noted that publications often skirted the issue and appeared reluctant to provide specific information. Overall, we found that intersectionality was largely not addressed in the papers that we found, subsequent searches found that this reflects broader trends in under reporting on intersectionality. The papers included in the scoping review rarely addressed First Nations communities, culturally and linguistically diverse, neurodiverse, people who experience disability, LGBTIQA+SB people and other systemic and cultural forms of intersectionality. Our research noted that intersectionality is often referred to very broadly and that the specific intersection between mental health and caring with other forms of intersectionality (e.g. culturally and linguistically diverse, disability, etc.) can become conflated. This raises interesting questions about the combination of experiences that researchers need in their research teams, participants and key stakeholders.

How experiences of mental health and caring intersect with other forms of intersectionality

People from diverse backgrounds are often underrepresented in mental health research and service design and delivery [8]. There is a need for Lived experience leadership to address how distress and caring intersects with other forms of marginalisation, and how this may impact how people with Lived Experience engage with research [53, 61]. Our review recommended that this gap in research intersectionality be addressed by connecting to the local community and exploring what their research needs are. Innovations such as the 'ALIVE Centre' [62] include an Intersectoral Committee to address these gaps. The *Translational Research Strategy 2024-2027* by the Victorian Collaborative Centre for Mental Health and Wellbeing applies an intersectional lens to mental health research, incorporating insights from stakeholders, mental health researchers, and the Lived Experience Advisory Panel (LEAP) [63].

While both publications share a commitment to ethical research and community engagement, *Keeping Research on Track II* centres on ethical research with Indigenous communities, and the Collaborative Centre strategy targets mental health care reform. Both incorporate intersectionality but differ in their scope and approach: *Keeping Research on Track II* provides a structured, ethical research framework for Indigenous communities, while the Collaborative Centres strategy uses interdisciplinary collaboration to reshape mental health care with an intersectional perspective.

First Nations people and communities

Another key resource is the National Health and Medical Research Council (also referred to as the "NHMRC") with support from the Australian Research Council (also referred to as the "ARC") and Universities Australia, *Keeping Research on Track II* offers a guide for conducting ethical research with Aboriginal and Torres Strait Islander Peoples [64]. This document emphasises intersectionality, acknowledging how overlapping identities—such as race, gender, and class—shape Lived Experiences within Indigenous communities. The guidelines promote respect, empowerment and inclusivity by highlighting the diverse, intersecting identities within Indigenous cultures and Lived Experiences. Five core objectives include: i) respecting Indigenous diversity; ii) ensuring community benefits; iii) promoting accessibility; iv) maintaining ethical standards; and v) fostering cultural continuity. This echoes priorities for First Nations health stated in The 'Fifth National Mental Health and Suicide Prevention Plan' [1] and Productivity Commission's inquiry [8].

First Nations and intersectionality

When we talk about the intersectional experiences of First Nations people in Australia we are looking at how different aspects of a person's identity (such as race, gender, or socioeconomic background) come together to create unique experiences [46, 63, 65, 66]. We may also like to consider the impact of the specific intersection between the experiences of First Nations people and mental distress, caring and intergenerational trauma.

Social and Emotional Wellbeing is an important part of First Nation's people's health. This concept considers the whole person, acknowledging that mental health may be closely tied to their family, community, culture, language and connection to Country [65]. Unlike Western approaches, which focus primarily on the individual, Social and Emotional Wellbeing highlights the importance of these relationships and how they affect one's total well-being. Mental health services for First Nations people need to respect this holistic view and include traditional healing practices alongside standard medical treatment to provide truly effective care and work with their local First Nations communities and leaders [65].

One of the major barriers for First Nations people in accessing mental health services is intergenerational trauma. The lasting impacts of colonisation—such as forced removals, loss of land, and suppression of culture—have caused trauma that's passed down through generations [64]. This has resulted in a deep mistrust of government services, including healthcare. It is important to recognise this history when providing care, as trauma-informed, practices that demonstrate cultural are crucial for building trust and delivering services that First Nations people feel comfortable using [67].

Discrimination is another challenge that First Nations people frequently face when accessing healthcare. This might emerge as racial stereotyping, a lack of cultural awareness, and other hurdles in healthcare systems. According to the 2022 Seclusion Report by the Victorian Mental Illness Awareness Council (VMIAC), Aboriginal and Torres Strait Islander individuals are more frequently secluded and confined in mental health settings than other groups [68]. While First Nation's people make up only 3.5% of psychiatric inpatients, they are engaged in 5.3% of seclusion incidents [68]. Such restrictive procedures can be extremely detrimental, re-traumatising and can cause major injuries, or even death [68]. These discriminatory experiences can result in delayed care, misdiagnoses and other poor health outcomes. Therefore, involving First Nation's communities in mental health service design can help address these issues by creating more inclusive and responsive care [46].

Cultural safety and cultural integrity is critical to providing effective mental health care for First Nations people. It entails providing an environment free of discrimination and bias, where people feel safe accessing services without compromising their cultural integrity [69]. This calls for healthcare providers to willing and consistently reflect on their own methods, learn about cultural differences and modify how they approach their work.

Research is also critical to improve mental health outcomes for First Nation's people. However, traditional research is frequently conducted on, rather than with Aboriginal and Torres Strait Islander communities, resulting in mistrust and, in some cases, detrimental effects [69]. To remedy this, community-controlled research is now being prioritised, with First Nations people participating actively in the research process. Involving First Nations people in research promotes the development of effective, culturally relevant mental health care, despite ongoing challenges such as limited funding and lack of culturally appropriate research methodologies [67].

It is also critical to understand how historical and systemic trauma plays a role in the mental health distress First Nations people experience today. Colonisation, racism, and ongoing social inequality have all contributed to poor mental health outcomes in First Nation's communities [66]. Working in genuine partnership with communities, reshaping the mental health system to prioritise and respect First Nations perspectives and needs, and making sure the system honours First Nation's culture, knowledge and experiences is necessary to address these issues.

Addressing these issues means reshaping the mental health system to centre and respect First Nations perspectives and needs, working in true partnership with communities, and ensuring that the system respects their culture, knowledge, and experiences [64]. First Nations leadership and community participation are crucial for successful mental health services. Research shows that when First Nations people are actively involved in every stage of creating and delivering services, outcomes improve [67]. Building trust between communities and healthcare professionals and promoting First Nations leadership and participation in decision-making results in better culturally relevant care [46].

We can improve the effectiveness and respect of mental health services for Aboriginal and Torres Strait Islander communities by comprehending the intersectionality of First Nations identity—the ways that historical, social, and cultural factors come together—and how important it is to addressing the mental health issues in these communities. This strategy fosters community healing in addition to improving individual wellness [65, 66].

The journey to allyship and partnership

The Royal Commission was an important milestone in an unprecedented recognition of the on-going harmful impacts of our mental health system. It demonstrated a shift from an expert position to a position of curiosity and inquiry about people's Lived Experience. This on-going journey of moving towards consumers, families, carers, supporters and kin requires a radical shift in power and embracing our unknowing. In this diagram you can see how each person needs to undergo a deep personal and transformative journey of realising that they "don't know" to genuinely value and integrate Lived Experience perspectives and create solutions by working together. We explore this further in the Case Study 4.

Case Study 4. Dr Catherine Brasier – A brief commentary

Dr Catherine Brasier – A brief commentary

Allyship is not a just something you just “lean in to”– this is a fundamental re-birthing of your understanding of who you are and where you stand. It is a deep and personal realisation that you **do not** and **cannot** understand the real-life reality of other people’s people lives. This hurts to realise. And through pursuing an on-going journey of allyship you are opening yourself up to the bumps and bruises that will set you free. For me, freedom was the realisation that I did not have to know everything, what I needed to do was work with the people who were most impacted by the problems I was trying to solve and the research questions I was trying to answer. It was realising that working together was the answer.

Research teams often follow a routine structure that often includes a number of roles which organised in a hierarchical structure. Table 1 provides and overview of this structure including role titles, responsibilities and how people with Lived Experience could be integrated.

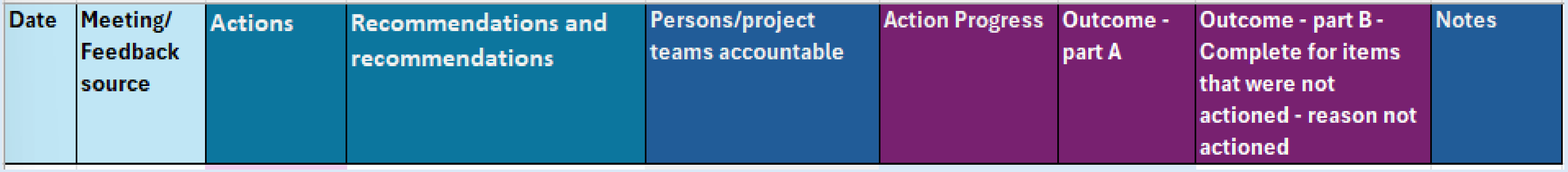
Lived Experience centred methods such as co-production are fundamentally about sharing power and making decisions with people who use services [58]. In a Lived Experience co-produced model people with Lived Experience need to be involved in the whole of the research process and have an active partnership with researchers. In that process, there needs to be a practicing of practicing power sharing between researchers and community. If there is not this partnership, then it is not co-produced research but research with people with Lived Experience. An example of a power sharing tool – the Lived Experience Action Log that was used in the Working It Out Together project below in Case Study 6.

__Case Study 6. 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 shareing and descion making processes?

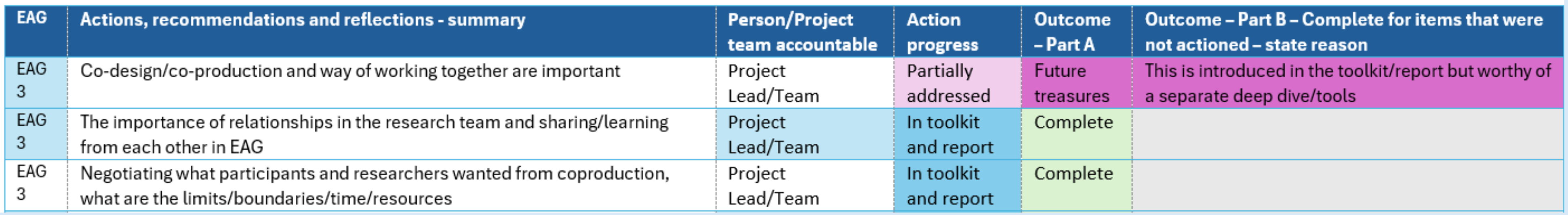
Step 1 - We developed a transparent power sharing process with our key stakeholders to ensure that we were accountable for how we included the input of our Expert Advisory Groups. This process was shared on an info sheet with the Expert Advisory Group members and discussed in the first meeting.

Step 2 - All actions, reflections and recommendations were recorded in the Lived Experience Action log during the meeting as a part of minute-taking. Here is a snapshot of the headings we used in the Lived Experience Action Log, see below.



Date	Meeting/ Feedback source	Actions	Recommendations and recommendations	Persons/project teams accountable	Action Progress	Outcome - part A	Outcome - part B - Complete for items that were not actioned - reason not actioned	Notes

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



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 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.

Methods, data collection, analysis and other ways of working together

Method, Collect and Analyse

Research Life Cycle Stages: 3, 4 and 5

Key Question:
How will you answer the research question by collecting and analysing data?

This section covers introduces information that is helpful in forming a research projects method - “Research Foundations”:

- Identifying a research question
- Human Research Ethics Committee

Then it presents a quick introduction to literature review, qualitative and quantitative research methods, including considerations for data collection and data analysis – “Research methods”:

- Literature reviews
- Qualitative research
- Quantitative research
- Co-production, co-design and other methods for working together

In this section we explore “how” we will investigate or try to solve this research question using a research method. A research method is a rigorous, repeatable and reliable approach to collecting, recording and analysing (or making sense of) information that can help us understand our research question. It includes all of the tools, processes, theories, assumptions and values which underpin how the research problem is defined, how data is collected and analysed to better understand a topic [70] and should consider if approval from a Human Research Ethics Committee is required.

Research foundations

This section introduces some key information that is important to developing a research methodology including identifying if you will need approval from an Ethics Committee and how to explore your research question.

Ethics in research

A foundational part of forming a method is deciding if an application to a Human Research Ethics Committee (also called a “HREC” for short, here in referred to as an Ethics Committee) is required. This has timeline, budgetary and planning implications and typically determines if the research study needs to develop a study protocol prior to commencement.

Who needs to use an Ethics Committee?

Most research that involves human subjects need to use an Ethics Committee. Proposals which are rated more than low or negligible risk need to be assessed by the organisations Ethics Committee [71]. Within a university, post-graduate students and staff need to have approval from an Ethics Committee. Mental Health services may not need to use an Ethics Committee if it meets the criteria for a Quality Improvement study. Intervention studies and trials typically require Ethics Committee approval and oversight.

What is a Human Research Ethics Committee (HREC)?

The Human Research Ethics Committees (referred to simply in this report as an Ethics Committee) are bodies in both private and public organisations that review research proposals pertaining to human studies to ensure that they are ethically sound [72, 73]. They are often referred to by their acronym “HREC”. The definition of human research is research which is conducted with/or about people, their biological materials, and/or data (information) about them [74]. They are a committee created by an institution or organisation to review research proposals and monitoring the ongoing welfare and rights of participants in that research [75]. Their main function in Australia is to “review research proposals that involve human participants to ensure that they meet ethical standards and guidelines” [73]. There are around 200 Ethics Committees in Australia which are guided by legislation and regulations which they must abide by [74]. They are found in universities, hospitals, government bodies and any other organisation which conducts research using human participants.

Ethics in research, and transgression against them, are extremely important and are increasingly becoming linked to the quality of research. They are a set of moral principles or rules of conduct [75]. There are four main areas to consider whether there is:

1. Harm to participants
2. A lack of informed consent
3. An invasion of privacy or confidentiality
4. If deception is involved [70]

All Australian universities have an Ethics Committee which approves and oversees research which involves human participants. *The National Statement on Ethical Conduct in Human Research* applies to all research with human participants [47]. All project involving human participants must gain an Ethics Committee approval through submission of an ethics application. Different projects are categorised as having different levels of ‘risk’. Negligible risk involves no expected risk of harm or discomfort to participants, ‘low risk’ may place participants at risk only of discomfort and ‘full’ application which involve vulnerable people groups [75]. Ethics Committees pay particular attention to projects including vulnerable population groups, such as those with Lived Experience and First Nations people.

The main roles of an Ethics Committee is to ensure that research merit and integrity, justice and benevolent treatment of human beings is maintained [76]. The purpose of the Ethics Committee is to safeguard the interests and rights of participants in research. The Ethics Committee does not just cover human participants but also relates to research such as examining records which contain personal information, anonymous surveys or are being observed by [73]. Institutions can develop their own processes for ethical review or utilise those of another organisation so long s as they are in line with the National Statement [71]. The National Statement on Ethical Conduct in Human Research sets the requirements for the ethical design, review and conduct of human research [47] and was last updated in 2023.

How can Ethics Committee help support Lived Experience-centred translational research?

Ethics Committees provide a safeguard by considering how researchers propose to collect, use, disclose and identify people and personal information [74]. They try to protect participants from potential harm, this also protects the researcher by demonstrating that they have adhered to specific ethical codes of conduct. Sometimes preconceptions or concerns about the “risk” from Ethics Committees can make it challenging to get approval for mental health and Lived Experience research. Getting approved by an Ethics Committee is important when applying for research funding as it is highly unlikely that major sources of funding will fund projects with Ethics Committee approval. It is also crucial when submitting to journal articles as it is now the nom that most peer-reviewed journals will not accept the publication results of studies which has not been approved by an Ethics Committee [77].

Ethics Committees can also be experiences as unhelpful as they can be time and labour intensive, most submissions will need to provide clarification or further information. The researchers then need to provide a response which is reviewed by the Ethics Committee, which can hold a project up for months [78]. Ethics Committee members can be experienced as paternalistic towards participants feeling over-protective [79]. Ethics Committee members can be seen as ‘gatekeepers’ towards what research is conducted. Their role is to interpret the National Statement but sometimes they do so arbitrarily so ethical research does not get approved [79].

Formulating the research topic and research question

Considering the need for an ethics application is often explored while the research team is formulating their research question. For some research projects this could limit the scope of what they can explore as intervention and higher risk studies require Ethics Committee approval.

Summary of FINER-M method for developing research questions

Methods such as the FINER-M framework are traditional ways of constructing a strong research question that can facilitate a study that will have academic significance [80]. The acronym denotes what are considered critical elements of a research question; that it should be feasible, interesting, novel, ethical, relevant, and measurable [80]. Table 2 below explores this framework.

Table 2. FINER-M framework for refining research questions

FINER-M	Description
Feasible	Is the scope of the research realistic? Are there sufficient resources available? Is the timeframe of the research reasonable?
Interesting	Is this research interesting to academics, researchers, and the wider community?
Novel	Will this research lead to new findings? Will it refute, support, or extend current knowledge?
Ethical	Will the research be approved by an institutional ethics board?
Relevant	Is the research relevant to the academic community, or the population it is studying? Does it promote or support future research?
Measurable	Will the outcomes of the research be measurable or quantifiable?

Source: Fandino et al., 2019 [81]

The FINER-M framework is a useful framework for developing a strong research question. It is an effective guide to support researchers in conducting research that is manageable and of significance to scientific, clinical, and wider communities. There is a movement in the research community that is advocating for research to be conducted with consumer involvement. For this summary, the “consumer” refers to the population impacted by the research findings. Dray, Palmer and Banfield [82] identifies that research is traditionally conducted “on” the consumer and not “with” the consumer, and this is decreasing the potential benefits of research outcomes. Contemporary research is finding that involving the consumer in the research process (e.g., as a participant, consultant, expert advisor, research assistant, etc.) leads to stronger, better focussed, and more rigorous research, and is yielding more significant findings, particularly in people focussed research fields such as mental health or social sciences [82, 83]. This presents an opportunity to reform how research is conducted.

The FINER-M framework is widely accepted and proven to produce quality, rigorous research questions. However, we propose a change to the framework that reflects the movement towards consumer-oriented research; the FINER-MC model to include consumers and carers (family, supporters and kin):

F – Feasible

I - Interesting

N – Novel

E – Ethical

R – Relevant

M – Measurable

C - *Consumer and carer-oriented*

This adjustment to the frameworks would encourage researchers to factor in consumer involvement and outcomes when designing their research project. This does not call specifically for consumer involvement in the research process, but for the research to, at minimum, be conducted with the aim of generating real outcomes for the consumer [84]. This adjustment could prevent time and resources being wasted on research that is disconnected from the consumer and is unlikely to yield relevant findings [85].

Furthermore, this change could empower the consumer to have agency over the research process, as research is historically developed, funded, and conducted by stakeholders in positions of power, with little agency given to the consumer [85]. Hence, if this change to the FINER-M framework is widely accepted, much more new research will be conducted with a consumer-oriented lens**.** Lived Experience-led frameworks for developing a research topic and research question could provide even better support for mental health researchers; this is an important area of investigation.

Research Methods

This next section explores some research essentials including literature reviews, research paradigms (quantitative, qualitative, mixed methods) and ways of working together (co-production, co-design and collaboration).

Literature Reviews

A literature review is a way of providing an overview of the current knowledge and information that exists about a particular area of research [86]. If properly conducted, a literature review will gather and synthesize existing research for the purpose of understanding what is currently known about that topic. This is done by searching academic databases utilising a predetermined inclusion and exclusion criteria, filtering out irrelevant literature, identifying the key similarities, differences, themes, shortfalls, and knowledge gaps of the research, and collating the findings in a concise writing piece known as a literature review [86, 87]. The main purpose for conducting a literature review could include [86, 88]:

- Identifying the gaps in current knowledge
- Examining the strength of current research
- Learning more about a particular topic
- Providing background information on new research or justifying new research

Literature review methods

Meta-analysis: A meta-analysis is the process of combining the findings of a significant amount of literature to increase the sample size and improve the statistical power of the findings for quantitative studies [89]. The meta-analysis can be used to generate a quantitative report of the findings of the included literature, thus producing high-quality evidence and a strong summary of current knowledge [90, 91]. Meta-analyses are typically informed by a research question and are performed with strict inclusion and exclusion criteria, and a considerable level of scientific rigor [90]. Meta-analyses can be performed as part of a systematic review, and are advantageous for identifying themes, trends, and significant statistics, as well as reveal potential strengths, weaknesses, gaps and biases in existing literature [90, 92].

Scoping review: A scoping review is like a systematic review, however, is considered broader and more exploratory for the purpose of mapping the current literature on a certain topic and identifying key themes, concepts, gaps in the literature, and opportunities for further study [93]. A scoping review still utilises a systematic approach to collecting and evaluating the literature through rigorous and transparent methods, however it produces broader overview of the literature, and does not attempt to synthesise the findings into a statement that guides practice decisions [93].

Systematic review: A systematic review responds to a research question by using systematic methods to explore, select, and analyse relevant literature using strict inclusion and exclusion criteria, and extrapolate data and findings from the literature [94]. This review minimises bias through rigorous method and control and attempts to analyse all relevant literature within the parameter of the study, and should be reproducible [94, 95]. A systematic review is advantageous for creating a quantitative summary of findings and is considered strong quality of research in academia [91, 95].

Narrative review: A narrative review is considered less scientifically rigorous than other types of reviews. This review involves conducting a broad search of the literature to gain an understanding of what is known about a topic, and to assess the literature that is available [96]. Narrative reviews do not focus on a narrow, specific research question, but rather on the broader research topic. Due to the broader, less rigorous nature of a narrative review, it can be more advantageous for assessing qualitative research and does not tend to collect or collate quantitative data [97]. One disadvantage to the narrative review is that it can contain higher levels of bias due to lower academic rigor involved in the literature search and inclusion and is generally not considered to be as strong as other types of literature review [96-97].

Qualitative research

This section provides a brief introduction to how qualitative research is conducted, its significance in the context of Lived Experience research, and the key methodological components that should be considered.

Learnings from the scoping review

Qualitative research was highly valued over quantitative research. Blueprint Writing Collective [98] demonstrated that young consumers were able to learn about research, be active co-researchers including qualitative data collection (i.e., interviews) as did Hancock, Bundy [99]. Sangill (2019) [6] found that user-researchers' experiences influenced data analysis by adding insight, depth and complexity to the analysis.

What is qualitative research?

Qualitative research is a diverse field that focuses on understanding the experiences of individuals or groups through non-numerical data such as spoken or written language [100]. It is conducted in various ways, including interviews, focus groups, and participant observation [101]. Qualitative research is an umbrella term that refers to a variety of different research methodologies. What these methods have in common is that they all focus on the *experiences* of a person or group, without using statistics or numbers to quantify these [101]. Typically, qualitative methods are used to understand why social phenomena are the way they are [100]. For example, why mental health consumers might be more likely to live in poverty, or why traditional researchers have not engaged with live experience experts in all research. It provides a rigorous way to understand the context of research questions [102].

The best ways to conducted high-quality qualitative research is an important question that is still debated in the research community [103], and in the Lived Experience community [104]. There are lots of different ways to do qualitative research and the specific design of any qualitative study will be based the purpose of the research, the research question, the needs and preferences of the community of potential participants, the expertise of the researchers, the funds and resources available and other factors.

A brief history of qualitative research

Qualitative research not only acknowledges the history that informs research questions [105], but it itself has a history. Qualitative research first emerged in imperialist movements of the early 17th century, when colonisers set about "studying" other racial types using a methodology which is now called 'ethnography' [106, 107]. In time, this developed into direct engagement with research participants. One prominent example is Du Bois's large scale qualitative study by interviewing 5,000 Black immigrants with the aim of understanding how to integrate this group into white protestant America [108].

Over time, research practices were further influenced by social movement in the 1920s and 1930s. The development of psychoanalysis – a particular way of understanding identity as constructed by past experiences [109] – has been key to the definition and popularisation of qualitative research. The new way of theorising people's experiences proposed by psychoanalysts gave legitimacy to the idea that people's reflections on their experiences are valuable, and qualitative research has come about as a product of this development 1920s and 30s [106]. Formal interviews and focus groups became valuable examples of qualitative research because of the role of psychoanalysis, and today we still rely on these methodologies – as we address in the 1930s [106].

The next big change in the practice of qualitative research came during the 1960's, when members of racial minorities who had previously been the subject of research coming to practice research 1930s [106]. This change in who was practicing qualitative research led to a broadening in the topics qualitative research was conducted on. Instead of focussing on racial minorities with the intention of assimilating them into the dominant social norms of white culture, researchers of colour broadened qualitative research to include a range of different experiences and perspectives not only related to race, and the academe followed on to produce the norms in qualitative research we have today.

Why qualitative research is important for Lived Experience research

Reflecting the themes described above, qualitative methods are particularly significant in Lived Experience research because they continue to empower individuals to share their stories in their own words [110]. This approach recognises the value of personal narratives and encourages researchers to listen actively to what Lived Experience experts wish to convey [111]. Techniques like interviews and focus groups can facilitate this engagement and foster collaboration between researchers and those with Lived Experience when conducted in a Lived Experience-centred way. In Lived Experience research, analysis methods that emphasise the subjective interpretation of experiences are vital creating an important niche for qualitative research. Methods such as narrative analysis, thematic analysis, and grounded theory can provide rich insights into personal accounts and social phenomena. Techniques such as triangulation, reflexivity and member checking allow qualitative researchers to reconnect to the participants to ensure that they are being faithful to their experience as well as adding to the researcher's rigour. Qualitative research provides many opportunities to include people with Lived Experience in the collection, and analysis and sensemaking from the data.

Qualitative data collection

Qualitative research can employ one or several key methods to collect data, and there is no consensus on which methods are best [103]. Rather, any of the below methods – and more – can be used alone or in conjunction with each other [112]:

Interviews: One-on-one meetings between a researcher and a participant, allowing for in-depth exploration of experiences. For example, researchers may employ a peer worker or Lived Experience researcher to conduct the interviews. These one-on-one conversations allow deep explorations of experiences. Interviewing people with Lived

Experience is a useful way to get in-depth insights. Interviews can be useful because they allow a lot of flexibility. This adaptability is especially important when researching complex or dynamic issues, or when the participant has knowledge that the researcher may not have foreseen.

Interviews may help build rapport between the researcher and the participant, managing the power dynamics that Lived Experience experts may be more sensitive to. Some researchers advocate having a conversation instead of a formal question and answer style format, as this helps to build rapport and disrupt the power dynamic of the researcher asking questions and recording participant's answers [113]. One of the limitations of the flexibility and adaptability of interviews as a qualitative methodology is that Lived Experience experts may redirect the conversation to the topic that they think is more important than the questions the researcher is asking [114]. This redirection from participants can also be a strength, as research participants may have insights into problems the researchers have not considered, but can be a barrier when funding or organisational mandates require the researcher to answer a specific question, and so it is important to engage Lived Experience experts in study design.

Focus groups: Group discussions led by researchers can gather multiple perspectives that are facilitated by one or more researchers, gathering diverse perspectives from multiple participants, often using the perspectives of other participants to spark discussion. For example, co-facilitation that combines a researcher and a Lived person with Experience is common, or a consumer and carer facilitator may be used. Focus groups are an excellent way to get in-depth and focussed information, some people prefer it to interviews because can produce high quality data as participants learn from and interact with each other [115]. While the benefits of doing focus groups are well established there are important considerations [116] relating to privacy and sensitivity of the research question. Some sensitive topics might not be suitable for focus groups, and might be better as interviews. There is no established rule about what topics should not be discussed in a group setting, and this is something researchers might like to seek advice from Lived Experience experts on. Generally, focusing questions on opinions rather than experiences can prevent distress, but this strategy should be employed as a part of a suite of measures to ensure that focus groups are appropriate.

Lived Experience experts can make their own decisions about if they are comfortable talking about the research topic with other participants. All participants should be offered the opportunity to participate in an interview or focus group [117]. More than one facilitator should always be present for a focus group to allow a space for debriefing as needed. Having a Lived Experience facilitator can help to alleviate some of the power dynamics between participants and researchers. This facilitator may have valuable insight into how the group could be run and how distress could be responded to, and so should be engaged in the study design phase of the research. All demographic questionnaires and consent processes should be completed one-on-one (or with a support person, as directed by the participant) so that participants have the opportunity to ask questions and say no to research requests free from any perceived peer pressure.

Written text: This may be utilised in lieu of conversational participation, allowing participants to respond to open-ended questions in their own time. For example, Lived Experience participants may complete a written reflection or provide photos addressing a theme (i.e. PhotoBox). These methods can occur in person or increasingly online, making participation more convenient and cost-effective [118] but face-to-face are also highly valued by people with Lived Experience [4].

Observation: Researchers watch participants in their natural environments to understand their behaviours. It is of paramount importance that any participants know they are being observed and understand what will happen with these observations.

People with Lived Experience of a mental health diagnosis may already have experiences of feeling observed (for example, in clinical settings) and so it is important that participants are given choice and control when using this research methodology. It is important that any risk of bias in interpretation of behaviour is managed, possibly by interviewing participants to discuss the observations collected [119].

These methods can happen in person or online, and written responses can also be collected, allowing participants to answer questions at their own pace. The most important thing is that researchers are honest with Lived Experience participants about their intentions and flexible to the needs of this group, who often experience a higher personal cost for participation in the research than researchers.

Analysing qualitative data

Qualitative research analysis involves a systematic approach to interpreting non-numeric data, typically written or verbal statements, gathered from participants. This process typically includes several key steps including:

Transcription: Spoken data from interviews and focus groups are transcribed into written form. This makes the data easier to review and interpret. Transcription can be checked participants for fidelity, there-by improving rigour and increasing Lived Experience input.

Coding: Researchers categorise the data into themes or codes. This is often done by two coders and can include a Lived Experience coder. This step helps identify patterns and significant concepts within the data, making it easier to draw connections and insights.

Use of software tools: Software like NVIVO or Dedoose have been used to facilitate qualitative research [105] and is now the most common way to analyse data. Tools like NVIVO and Dedoose assist researchers in organizing and analysing qualitative data. These platforms help manage large volumes of text, facilitate coding, and visualize relationships within the data. People with Lived Experience can be trained to use these platforms, they are relatively user friendly. These steps are usually combined with an overarching analysis or methodological framework. Some of the methodologies for qualitative research include:

Narrative analysis: Focuses on the stories shared by participants and analyses how individuals construct meaning through their narratives. It emphasizes the context and structure of the stories to uncover insights into personal experiences and explores how individuals construct their identities and understand their lives through storytelling [120].

Its purpose is to:

- To explore how narratives shape and reflect personal and social identities
- To understand the context, structure, and content of stories, revealing underlying themes and cultural meanings

Key characteristics include:

- Emphasising on storytelling by paying close attention to the narrative structure (e.g., beginning, middle, end) and the language used by participants
- Creating contextual understanding by considering the socio-cultural context in which the narrative is situated, exploring how it influences the meaning of the story.

- Focus on individuals’ experience. This approach seeks to understand the personal significance of the narrative for the storyteller, often highlighting unique perspectives.

Thematic analysis: This method codes and themes data to identify overarching themes that capture the essence of the participants' experiences. Researchers look for commonalities and differences, providing a deeper understanding of the subject matter. This is an interpretive step, and different researchers might have different perspectives about themes in the same data. Thematic analysis is a method for identifying, analysing, and reporting patterns (themes) within qualitative data. It is flexible and can be used across various theoretical frameworks.

Its purpose is to:

- To systematically organise and interpret data by identifying key themes that capture important aspects of the research question
- To provide a rich description of the data while allowing for some level of interpretation

Key characteristics include:

- Flexible frameworks that can be applied to various types of qualitative data (e.g., interviews, focus groups) and is not tied to a specific theoretical framework
- Inductive or deductive analysis that can be conducted in an inductive manner (data-driven and generative way) or deductively (based on existing theories or literature).

Grounded theory: Grounded theory is a systematic methodology that aims to generate theories grounded in qualitative data. Rather than testing existing theories, it seeks to develop new theoretical insights directly from the data collected.

Its purpose is to:

- Understand social processes and phenomena through the development of a theory that is closely tied to the data
- To provide a framework that explains how and why certain patterns or experiences occur

Key characteristics include:

- Data collection and analysis that involves simultaneous data collection and analysis. Researchers often conduct initial coding, collect more data, and refine their codes iteratively
- Constant comparative method that involves comparing new data with existing codes and categories throughout the research process, allowing for the theory to evolve
- Theoretical sampling that can be used to guide data collection, choosing participants and data sources that will help further develop the emerging theory

Ways of enhancing Lived Experience contributions and increasing their impact

This section considers research practices often used by qualitative researchers to ensure that they confirm or validate that they have understood the findings and that they have fidelity to what the participants have shared.

Reflexivity: Involves practices and exercises that supports researchers to become aware of their own biases, perspectives, and positionality throughout the research process. It requires them to critically reflect on how their background, experiences, and beliefs may influence the research design, data collection, and interpretation. This can be done through reflective exercises, including co-reflection for Lived Experience researchers, journalling and Lived Experience-centred supervision.

Member checking: To enhance validity, researchers may ask participants to review the findings and interpretations, ensuring their voices are accurately represented. This step allows participants to check that researchers have reflected the meaning of what they have shared and have not misunderstood or co-opted their comments or taken them out of context.

Awareness of bias: By acknowledging researcher biases, researchers can try and minimise the impact of this on the study, ensuring that the findings genuinely reflect participants' perspectives rather than the researchers' preconceived notions. Consultation and reflection with Lived Experience experts who hold power, expertise and authority on the topic can assist this.

Transparency: By documenting research reflections, researchers provide readers with insight into how their views may shape the research. It is important that researchers are transparent and authentic about how they relate their experience to this and are clear about this impact their research.

Improved engagement: Reflective researchers are often better equipped to build rapport with participants, as they approach the research with humility and openness to learning from those they study. This can include providing options for compliments, complaints and feedback, as well as Lived Experience support/debriefs.

Triangulation: These components contribute to building trust and ensuring that the voices of Lived Experience experts are authentically captured. Understanding how qualitative research is conducted and analysed is essential for establishing common ground between researchers and individuals with Lived Experience. By valuing personal narratives and actively engaging with Lived Experience experts, researchers can create more inclusive and impactful studies [14]. Qualitative research is a tool that traditional researchers and Lived Experience experts alike can use to ensure consumer perspectives are used in research.

Implementation: Researchers can practice reflexivity through journaling, peer debriefing, and ongoing self-reflection during the research process. They may also include a reflexive section in their reports to discuss how their positionality affected the research.

Best practice in qualitative Lived Experience – centred research

Our scoping review did not address research conducted by people with Lived Experience considering the importance of this body of work we have included a sample of current best practice qualitative research. These are presented below. These best practice examples of Lived Experience-centred research in Case Study 7:

Case Study 7. Best practice in qualitative Lived Experience–centred research

Best practice in qualitative Lived Experience–centred research

Employed but not included: The case of consumer-workers in mental health care services.

Edan, V., Sellick, K., Ainsworth, S., Alvarez-Varquez, S., Johnson, B., Smale, K., ... Roper, C. (2021). The International Journal of Human Resource Management, 32(15), 3272–3301.

This is a leading example of Lived Experience led qualitative research. It is published in a Q1 journal, meaning that it is published in the top bracket of journal rankings. It also has many authors who are writing from a Lived Experience perspective, and who are employed in lived experience identified roles, partnered with non-Lived Experience experts. The first and last author are both Lived Experience experts. This is important because the first and last positions are the most important on a paper – the first author is the one who has done the majority of the work, and the last is the most senior – often the person who oversaw the grant.

The authors describe this paper as co-production, with a consumer worker action group established to deliberate on the project, with the Lived Experience researchers as the primary point of contact for this group. The article explores the history of the Lived Experience workforce, grounding the Lived Experience involvement in the article.

Aims: The researchers explored the experience of employees with mental illness (consumer-workers) and their perception of inclusion and exclusion in their roles in mental health care service settings, specifically in relation to Human Resources (HR) practices and processes.

Method: The researchers used a mixed method study design with principles of co-production. The co-production principles used were described as sharing elements of action research and rejecting ideas of researchers being 'detached from the phenomena they study' (p. 3282).

A Consumer-Worker Action Group (CWAG) was established comprising four academics (two of whom had consumer expertise), four co-researchers with experience working as consumer-workers, and a Department of Health and Human Services representative. The group informed the design, implementation and analysis of the research.

A multi-phased mixed method approach was used to conduct online surveys, semi-structured interviews and a focus group comprising of nine participants who had previously completed the survey or an interview.

The online survey was developed by the CWAG and included Likert scales, multiple choice, and open-ended questions, while the semi-structured interviews prompted participants to provide further details and reflections about their experiences as a consumer-worker. The only survey was piloted with four consumer-workers, who provided feedback, before being distributed ‘amongst consumer-worker networks in Victoria’ (p. 3283).

Analysis: 77 surveys and 14 semi-structured interviews were analysed ‘for inter-rater reliability and any significant discrepancies in coding’ (p. 3284). The focus group then reviewed the data to validate the findings.

Findings: The findings were ‘categorised around three topics: consumer-workers’ experiences of workplace inclusion/exclusion, discrimination and bullying; the organisation support they experience for their role; and the extent to which their role is recognised and understood within the broader mental health service’ (p. 3285).

The results suggested that consumer-workers experience:

- Forms of marginalisation, exclusion and discrimination were experienced even where participants indicated some level of inclusion in their workplace
- Many participants reported that they felt understood and valued, mostly by consumers and colleagues, while also feeling ‘judged because of their Lived Experience and treated differently than colleagues’ (p. 3293). This was found to undermine ‘their confidence and capacity to contribute’ (p. 3293)
- Many participants experienced significant material inequality, including less pay, more precarious employment, less industrial representation and fewer opportunities for professional development
- Mechanisms for resolving grievances and discrimination were found to be ineffective for consumer-workers in their roles

- Positive experiences accessing reasonable adjustment processes under disability provisions although Human Resource processes posed a challenge
- Stigmata and discrimination were common experience in the workplace

Conclusions: This study emphasized why alternative ways of conceptualising and providing support to consumers of mental health were important to consumers and that this could be supported by better organisational and Human Resources processes.

Keeping it real': A qualitative exploration of preferences of people with Lived Experience for participation and active involvement in mental health research in Australia.

Dray J, Palmer VJ, Banfield M. 'Health Expect. 2023; 27:e13934.

Background: This is a leading example of Lived Experience led qualitative research, with the lead author identifying as a Lived Experience research fellow, working alongside other academics.

The authors describe this paper as exploring research with, other than research on, participants, and the preferences of this with Lived Experience in research engagement.

Aim: The researchers aimed to explore the preferences of people with Lived Experience for engagement with research' either as participants or in more active roles within the research.

Method: Data was collected from three separate Lived Experience studies conducted over nine years from 2013 to 2022, as well as two group discussions and an online survey.

The first study was a large group forum conducted in 2013 at an Australin Capital Territory Consumer and Carer Mental Health Research Unit event. The forum comprised 24 people with Lived Experience either as a consumer or carer.

The second study involved two online groups aimed at gathering data on Lived Experience preferences of engagement with mental health research in 2021. Eleven people participated in the online groups.

The third study involved an open-ended online survey that was advertised through consumer and carer networks, social media, and mental health organisations across Australia. This study included 365 participants with Lived Experience as a consumer or carer.

Analysis: Inductive thematic analysis was undertaken for all data sets.

Findings: Lived experience is critical for mental health research. High levels of knowledge and expertise in mental health research should lead to knowledge generation and research agendas.

Conclusions: There is a critical a need for a space to share experiences and stories, and flexibility in research methods where people with Lived Experience have equal power.

'I was having an anxiety attack and they pepper sprayed me': police apprehension in mental health contexts in Australia.

Randall, R., Kennedy, H., Karanikolas, P., Bashfield, L., Rayner, A., ... Nguyen, F. (2024). Policing and Society, 1–16.

Background: This is an example of Lived Experience research, completed with both Lived Experience and non-lived experience authors.

The authors describe this paper as exploring police intervention in mental health contexts and the trauma and other difficulties this presents for people with mental ill health, as well as the lack of Lived Experience scholarship surrounding this issue.

Aim: The research explored the experiences of people who were apprehended by police in the context of a mental health crisis in Australia.

Method: Co-production was implemented to involve people with Lived Experience in collaborative conception, design and analysis'. Lived experience researchers worked alongside non-lived experience researchers to design the study.

The research was completed over 10 months from 2021 to 2022 and included semi-structured interviews with 20 participants who had been apprehended by police at least once in a mental health context.

Analysis: Data from the interviews was analysed using the 'DEPICT' approach and involved a six-step process for conducting collaborative qualitative analysis with individuals with Lived Experience. The steps included: i) dynamic reading; ii) engaged coding development; iii) participatory coding; iv) inclusive reviewing and summarising of categories; v) collaborative analysis, and; translation.

Findings: Covered all aspects of police responses including prior to police contact (i.e. experiences of social and economic disadvantage), the experience of apprehension, use of force, and coercion. Disadvantage prior to police contact was felt as universal for participants who had experienced police apprehension.

- Service systems interact in unhelpful ways, including being inaccessible, culturally unsafe, and crisis-driven
- Police apprehension increased mental distress
- Police apprehension was common in the family violence context, with some participants reporting their psychiatric diagnosis being used against them to police by a perpetrator or exacerbating the mental health crisis
- Use of force by police is common and over-used in mental health contexts
- Material vulnerability was a common experience after police involvement
- Distrust in services was increased following police involvement
- Connection with others and community was experienced by participants as helpful

Conclusions: The participants preferred police non-attendance, peer led responses, and co-response models (in some circumstances). There needs to be more emphasis on human rights.

Quantitative research

This section provides a brief introduction to quantitative research, its importance in the context of Lived Experience research, and some key methodological components that should be considered.

Findings from the scoping review

The review identified that are a small number of few Lived Experience researchers who are making quantitative research. There were very few quantitative studies in general, this is reflective of overall trends in Lived Experience research which prefer qualitative methods compared to quantitative methods. Of note, both quantitative studies included were by the same lead author [121, 122] who is an ally researcher. A small number of mixed methods studies were included [123-125], all of which were completed recently. There needs to be news ways of understanding, exploring and sharing as quantitative data that is safe, effective and in line with Lived Experience centred-research.

An example of the use of quantitative data is the Productivity Commission's 'Inquiry into Mental Health' [8] stated that Australian, State and Territory Governments should agree on a set of targets and timeframes that specify key mental health and suicide prevention outcomes. The Productivity Commission stated that these targets should be co-designed with consumers and families, carers, supporters and kin and include both quantitative and qualitative evidence and data. Furthermore, it recommended that Aboriginal and Torres Strait Islander people and the National Federation Reform Council Indigenous Affairs Taskforce should be included in discussions about any targets that may affect Aboriginal and Torres Strait Islander people (Action 24.4) [8]. This should include considerations around quantitative and longitudinal research.

What is quantitative research?

Quantitative research is an approach to research that utilises statistics and data to analyse findings, and can be used to identify and understand patterns, correlations, and general results [126]. Quantitative data collection methods include surveys, controlled scientific experiments, and observations [126]. Quantitative research focusses on objectivity and replicability, allowing researchers to generate academically rigorous findings, and draw significant conclusions based on data [127]. This type of research is commonly used in social sciences, health, and education, and seeks to identify causal relationships or correlations within data sets [70]. By utilising statistical analysis, researchers can generate findings that are reliable and valid, that supports decision-making and provides a basis for further exploration or interventions [70]. Quantitative research is considered to have sound accuracy and academic rigour when performed properly and ethically.

A brief history of quantitative research

Quantitative research is rooted in early mathematic and statistical decision making, particularly in relation to gambling and calculating insurance risk [128]. This early implementation provided a foundation for the application of quantitative research in modern science. The 17th century saw the rise of prominent scientific figures such as Isaac Newton and the formulation of theories such as probability theory, a period in which observation, measurement, and data analysis saw prolific development [129]. By the 19th century, advances in statistical tools saw a significant increase in the use of rigorous data analysis and interpretation [70].

In the 20th century, quantitative research gained prominence through advancement in technology and statistical research techniques [128]. The development of computing tools empowered researchers to handle larger and larger datasets, giving rise to new approaches to quantitative research [102]. Currently, quantitative research is a broad and well understood method of research and has strong application across many research disciplines, and modern technology and research frameworks enable researchers to analyse and understand vast amounts of data to produce relevant research findings [130].

Why quantitative research is important for Lived Experience research

All methods of quantitative data collection have relevancy to Lived Experience research. However, some methods lend themselves better to Lived Experience than others. Quantitative research has been criticised as impersonal or used to objectify people understanding it allows people with Lived Experience, and their allies, to challenge common stigmatising assumptions and connect into important mental health and population data. Quantitative research can prove the effectiveness of interventions so that they can be implemented in our communities by establishing generalisability. Quantitative research is able to capture important changes over time including changes in satisfaction and the longitudinal impact of interventions. Quantitative research can answer questions that compliment or triangulate qualitative and philosophical findings.

Quantitative data collection

Quantitative research can be collected through several methods that produce numerical data. This data can be collected, analysed, and summarised by researchers. Data collection methods include results [126]:

Structured observations: Observations carried out in a systematic matter with findings coded to generate quantitative data for analysis [131]

Surveys: A method of gathering vast data from a large participant base, surveys ask predefined questions to participants and allow researchers to maximise participation and minimise disruption to the participant [129]

Controlled experiments: Researchers produce findings by manipulating variables in a controlled environment and recording the data [132]

Standardised testing: The use of a predetermined standard to measure results, such as a psychological assessment or a high school mathematics test [70]

Secondary data analysis: Analysing pre-existing data to generate new knowledge, such as a meta-analysis of existing literature in a specific field [133]

Quantitative data collection

Surveys allow researchers to collect sizable datasets from large populations that identify with Lived Experience [84]. This can empower people with Lived Experience to answer questions honestly and provide sound data to researchers due to the anonymity of surveys. Moreover, researchers can collaborate with people with Lived Experience to create survey questions that are relevant, appropriate, and do not threaten the safety of participants. Further to this, structured observations can be practical for Lived Experience research as it allows researchers to analyse and code behaviours, interactions, and events that would be difficult to study in other ways. The observation and recording of phenomena, and the subsequent coding of this data, can be completed in partnership with people with Lived Experience, and can facilitate rigorous quantitative research. Use of big data refers to accessing large data sets, usually collected and owned by state or federal governments. These data sets usually contain data that’s been collected in health or justice systems. This data can be used by governments for them to build an understanding of the needs of populations, and can be accessed by researchers under strict conditions. Lived Experience experts can and should be engaged in the use of this data for research purposes, as the way that questions are framed and the ethics around this data is open for interpretation.

Analysing quantitative data

Researchers analyse quantitative research using methods of collecting and summarising data and drawing conclusions on findings [134]. Following data collection, the themes and variability of the data is determined using informative statistics, such as the means, medians, standard deviations, and outliers within a dataset [134, 135]. An inferential statistical analysis is then used to generalise findings, while methods such as regression analysis, t-tests, and analysis of variance can test research hypotheses or identify relationships between variables [135]. The result of this process is the potential opportunity for researchers to report significant findings, make informed decisions or recommendations, or determine what further research may be needed.

There are a range of statistical analysis methods, most of which are conducted using specialist statistical analysis computer programs. Quantitative data can be analysed through many different methods or processes. This includes:

Informative/descriptive statistics: data that describes the people or phenomena in the study such as the mean, median, standard deviation, and outliers of their age, gender, education etc [135].

Inferential statistics: using methods such as regression analysis, t-tests, and analysing variances in the data that suggests a generalisable pattern [134].

More complex methods of analysis can also be used, such as a multivariate analysis, structural equation modelling and others.

Ways of enhancing Lived Experience contributions and increasing their impact

Quantitative methods are not fixed, and researcher preferences and biases can influence research processes and consequently research findings [136]. Lived Experience experts can influence how quantitative research is constructed and the way that questions are asked. This work is being done in other disciplines – for example, Conigrave et al. [137] conducted a randomised controlled trial of a program to reduce harmful alcohol consumption in Indigenous communities which engaged with Lived Experience experts but engagement in quantitative research in mental health has yet to be fully explored.

Co-production, co-design and other methods for working together

This section introduces co-production, co-design and other ways of working that centre Lived Experience. These ways of working are most often applied to qualitative methods although they also lend themselves to quantitative and mixed methods research.

A brief history of co-production, co-design and other methods for working together

Co-production and co-design in mental health research plays an important role in allowing different voices to be heard and increasing Lived Experience empowerment [16], although this model is often co-opted by non-Lived Experience researchers to increase the appearance of Lived Experience input while maintaining power and control over key parts of the research (e.g. identifying and defining the research problem, study design and interpretation of results). Lived Experience contributions involve a unique personal, emotional and often painful investment by individuals with Lived Experience into their work which is routinely underestimated and under supported in non-Lived Experience-led research projects. It is rare to see best practice recommendations such as consumer perspective supervision, debriefing or mentoring to protect Lived Experience contributors from isolation and help them to feel connected, supported and learn from someone else's experiences [138]. Currently, most mental health consumers are very disconnected from contributing to mental health research and cannot access the findings of mental health studies due to the exclusive nature of peer reviewed articles.

Why co-production, co-design and other methods for working together is important for Lived Experience research

Co-production is about collaborating together around a shared goal. It is about bringing together different perspectives and collaborating to design a shared solution. It is a method to support curiosity and creativity. In this project the dominant perspectives are mainstream research, Lived Experience research and Lived Experience professionals, all with unique expertise and insights. In order to create a psychologically safe space, differences of perspective need to be given space to openly share whilst acknowledging their distinct and collective value [14]. To successfully co-produce mindsets of exploration and learning need to be established to create a culture or reciprocity.

In co-production, Lived Experience is involved or leading the planning, design, delivery and evaluation. To be co-production all these phases need Lived Experience engagement or leadership, though each phase can be a standalone collaboration activity. Co-production is a high level of engagement, where Lived Experience leads from the outset and Lived Experience is engaged in the initial conceptual planning stage [16].

Power is about the about the ability to influence. Decision-making is about who makes decisions, and how they go about making those decisions. Co-production methodology is about introducing practical ways for power to be identified, explored and shared by those who hold power. Understanding a research process and having influence over how research is generated is one way that researchers have power in comparison to those that do are not researchers. Every project has limitations, whether that be timeline, accountabilities or budget. To do so requires transparency around decision making processes and intentionally sharing power. It also requires open and active discussion around the limitations and decision-making processes [14]. By utilising co-production methodologies Lived Experience capacity, skills and confidence is built. Lived experience ways of knowing an expertise is often excluded from determining the research agenda. Building the capacity of Lived Experience capacity is another way that power is shared in co-production activities.

Data collection for co-production, co-design and other methods for working together

Co-production and co-design are creative processes so visual arts methods such as can be more engaging and have more mutual benefit than traditional methods. For example:

- Story boarding
- Artistic methods
- Plays
- Models and prototypes
- Photographs/PhotoBox

A robust evaluation uses a combination of methods, and in co-production providing partners with a choice of methods as a trauma-informed approach. These creative approaches are participatory methods of data collection that enable partners in co-production to meaningfully contribute to the research process. These methods are collaborative processes of generating data that empower people to express their unique perspective. This is particularly useful for people with Lived Experience as these methods can portray aspects of their Lived Experience that verbal methods might not uncover, especially if they have not had access to academic privilege. This process can promote a sense of empowerment and identity as well as a shared identity in the co-production activities.

Analysing co-production, co-design and other methods for working together

Data analysis should be completed by a collaborative team of people with Lived Experience and may include non-Lived Experience researchers when required. To analysis the creative methods comprised several phases of thematic analysis and constant comparative methods. Qualitative data analysis methods involved understanding the data, identifying patterns, and developing theories [102]. Qualitative research methods of content and thematic analysis could be used.

Ways of enhancing Lived Experience contributions and increasing their impact

Research team meetings, community sense checking and engaging Lived Experience experts can help the findings come together, although maintain transparency and power sharing is essential. Co-production in particular specifies that the research should be Lived Experience driven and the Lived Experience people involved must reflect the specific experiences and phenomena that is being explored [16].

Expert Advisory Groups

Careful and considered planning is essential for the success of an Expert Advisory Group. A well-structured Expert Advisory Group can assist in the development of genuine partnerships between participants and the research/project team, ensuring the project is impactful for the relevant community or topic. It is crucial to provide adequate resources and adhere to sector expectations, including ensuring remuneration policies aligned with peak body requirements. Developing a Terms of Reference can be beneficial, outlining project scope and purpose, roles and responsibilities and attendance requirements. When recruiting Expert Advisory Group members, it is important that the group's members reflect the diversity of the community or topic being researched. Co-facilitation is effective in fostering a collaborative environment that encourages participation and can help minimise power imbalances. Action logs can track key contributions and improve the functioning of the Expert Advisory Group. Documents like Brave Space Agreements can help set the tone for how members engage with each other, although some people prefer alternatives to this. Ensuring members have appropriate support throughout the Expert Advisory Group (e.g. providing access to peer support/de-briefs with co-facilitators/chairs) is essential. Expert Advisory Groups are further described in more detail in the toolkit. This information adds detail about different types of advisory groups as well as Terms of References.

Definition Box 1. What is the difference between an Expert Advisory/Decision-Making Group and other committees?

What is the difference between an Expert Advisory/Decision-Making Group and other committees?

When we talk about Expert Advisory/Decision-Making Groups, we mean any formal co-ordinated groups that include Lived Experience members and other key stakeholders that we ask to come together to provide targeted advice to inform the project. Members of the Expert Advisory/Decision-Making Groups generally are not the project investigators, although some Expert Advisory/Decision Making Groups do contain a combination of external experts and research investigators/team members.

At times you might hear these kinds of groups called by other names, for example:

- Consumer and Carer Advisory Group (CCAG), Lived Experience Advisory Panel (LEAP), Lived Experience Advisory Groups (LEAG) – Advisory groups made up of consumers and carers, family, supporters and kin to advise on quality and service improvement
- Consumer/Carer Forum – Generally used in later stages of a project to provide consultation/consumer/carer feedback, does not necessarily have decision-making role
- Steering Committee – Used generally for high-level strategic advice and direction, may have varying levels of decision-making
- Expert Advisory and Decision-Making Groups provide Lived Experience Expertise and has a decision-making role in the project

There are always new kinds of groups – research is a rich and diverse field!

Feedback and suggestions should be sought from the Expert Advisory/Decision-Making Group members throughout the project. Opportunities to work together and share expertise optimise the translational aspect and should consider intersectionality, accessibility and wellbeing.

Develop the Expert Advisory/Decision-Making Groups 'Terms of Reference'

For projects that are utilising an Expert Advisory/Decision-Making Group, developing Terms of Reference can make sure that there is transparency about the scope and power sharing/decision-making power of the members. Some key questions you may want to explore include:

1. What are the key values and principles of the project?
2. How would you introduce the project? *(e.g. What is the research topic and the research question that you are trying to answer? Who is in the research team?)*
3. What is the purpose and scope of the Expert Advisory/Decision-Making Group?
4. The membership of the group including who the Chair/Co-Chairs are
5. How will decisions be made (quorum, consensus, etc.)?
6. Rules, roles and expectations (frequency of meeting/location, ratifying the Terms of Reference, proxy attendance, etc.).
7. Feedback and suggestions for quality improvement for the group

Share

Share
Research Life Cycle Stage: 6

Key Question:
How will you share the findings with participants, the organisation and external key stakeholders?

This section provides some considerations for sharing information and the findings throughout the research project. When sharing it is important to use plain language, include a summary, make it accessible (disability, visual, hearing, neurodiversity, culturally and linguistically diverse, First Nations) and include pictures and diagrams, basic fact sheets and glossaries. Projects and activities need to explain how academic findings translate into real-world research and what this means for people with Lived experience. Creating multiple ways to connect and share information such as peer-reviewed publications, YouTube etc. Many people with Lived Experience cannot access peer-reviewed journals so it is important to consider publishing in open-access journals which are accessible to them.

There are multiple barriers to sharing information by people with Lived Experience researchers. These include not being listed as authors on peer reviewed papers which create obstacles to developing a track record for career Lived Experience researchers . [123]. As well as a lack of Lived Experience forums to share and generate research ideas. The use of social capital to promote the work of Lived Experience researchers is one strategy which could be used.

Strong communication is important and there are multiple ideas ways in which ideas can be shared. Peak body’s (such as Tandem, VMIAC etc.), organisational consumer lists, registers and newsletter can be used to connect with consumers. Research can be communicated through forums, facilitated groups as well as conferences and symposiums to educate people about opportunities and share ideas. It is also important to let research participants and research team members know the results of the study, the impact it had, what it led to and end a study by sharing an executive summary or results of the study without participants having to ask or follow up. By doing this, you increase the confidence of participants and acknowledge the importance of their time and knowledge. As with all stages of research, intersectionality should be considered. There needs to be an inclusion of First Nations people. Currently, there is very few publications which mention First Nations people involvement in the dissemination of research. Co-production and co-design are essential.

Chapter 3 – Tracking and evaluating the impact of Lived Experience in research projects

Overview

This chapter provides information to support researchers to track and evaluate the impact of Lived Experience input in research.

- What we learned from the scoping review
- Indicators of success
- Impact
- Outcome tools
- Accountability

What are the key takeaways from this chapter?

Advocate – Researchers have not always been transparent about the degree that their research has been impact by the people with Lived Experience who have helped them develop and conduct their research

Implement – This part demonstrates that there are practical tools and concepts that can help researchers track and report the impact of Lived Experience researchers

Evaluate – This chapter completes this report by underscoring the importance of researchers evaluating their own process and being transparent about the authenticity of research that claims to be Lived

This section explores the role of monitoring and evaluation in showing the impact of Lived Experience-centred translational research. It has been noted that Lived Experience and peer work is the only discipline which has to provide evidence that it is effective. None-the-less, evaluation that is conducted using Lived Experience values can make important contributions to understanding what works well from consumers, families, carers, supporters and kin. This area was not strongly addressed in our scoping review; this could be owing to the focus and criteria used. Further research is recommended.

Within the ongoing development of embedding Lived Experience involvement, expertise and leadership in systems, structures, policies, processes, practices programs and services a parallel development of processes and governance structures to guide systems transformation will be necessary. This may include simultaneous development of a scope of practice and practice framework to govern and review practice. While this creates burden of additional work and has the potential to present unique challenges, this is an opportunity for greater cohesion and alignment of ideal and actual practice standards and workforce capabilities. Innovation and continuous improvement within the context of Lived Experience governance includes enabling and promoting adaptation and innovation towards the framework itself, alongside other frameworks, decision-making guidelines and accreditation processes. There is an urgent need to revise the impact and delivery of clinical governance process which can be a pre-requisite attached to grants of and quality improvement processes with human rights and other legislations/policy, by ensuring rights are embedded in service planning and evaluation.

Indicators of success

The Victorian Lived Experience Engagement Framework [139] states that their key engagement principles are: we are purposeful; we are prepared; we are genuine; we are inclusive; we communicate. As part of the evaluation, the first step is to identify the goal, whether there is low medium or high engagement and provide indicators of success for these. It is the perspective of this project, that high levels of engagement and Lived Experience leadership should be best practice.

In a systematic review argued that co-production is promoted as useful way of improving the quality of health and social care however due to the multiplicity of measures used their outcomes are difficult to interpret [140]. They stated that researchers should be mindful about impact on participants. They also noted that co-production can improve well-being, self-confidence and empowerment, although participation can also lead to feelings of uncertainty and vulnerability. They noted that the there is a difference between positive outcomes and goal fulfilment in co-production. Various measures were used but the goal levels were often not set before the projects [140].

Previous research has reported that co-produced services have both costs and benefits which can act as disincentives. Their impact is often longer term which makes them difficult to accurately assess and/or measure. A review by Hanlon et al. [141] which aimed to evaluate the role and effectiveness of co-produced suicide prevention interventions in adults found that one limitation of co-produced research is that stakeholder involvement is mainly limited to the co-design of the intervention which limits them from other important aspect of the project for example delivery and intervention evaluation and impact. They stated that Including stakeholders in the latter stages of the research project is important.

Impact

Impact can be conceptualised and defined in different ways, including societal change, changing people's lives, research relevance and stakeholder knowledge and practices [142]. Person-Defined Impacts can include people with Lived Experience who are interacting with or being supported by an organisation to have opportunities to demonstrate the value and impact of initiatives. This can include evaluations of safety, quality and intervention evaluation for reporting and funding purposes. This can play a vital role as they measure how people impact and interacting with an organization can play a role in determining how its value and impact of is measured.

Outcome tools

There has been of the ability to combine validated outcome tools and co-production found tensions between the two. While some people have expressed that it was difficult to combine them into a mixed method research design, due to the quantified outcome tools increasingly used in evaluation research this may be due to other factors such as limits within the researcher expertise and preferences about doing so [143]. They argued that this risked making public participation tokenistic. Currently, there are insufficient standardised or validated measures that are based on Lived Experience conceptions and phenomena.

Accountability

Accountability means that organisations, services and leaders are actively responsible for monitoring, recording and sharing how well they have met the expectations of people with Lived Experience – including impact of services and supports and how they were experienced. This can include how people with Lived Experience (e.g. Lived Experience leaders and peer roles) are being supported and listened to. It can include how organisations report their impact and how people with Lived Experience are involved in decision-making and governance processes. Accountability ties a services action with its value, purpose and strategy. Ideally it should provide a psychological safe space to non-judgementally check in, challenge and improve how things are done.

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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 (Discipline Lead - 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)

Other Lived Experience and research toolkits

Supplementary Table 1. 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 University of Sydney	2007, updated 2024	✓	✓	✓	https://cmhdaresearchnetwork.com.au/resource/research-essential-for-the-community-sector/

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 diseases, and mental health and neurological conditions	World Health Organisation	2023	✓	✓	✓	https://iris.who.int/bitstream/handle/10665/367340/9789240073074-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.mindaustralia.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/Coproduction_putting-principles-into-practice.pdf

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