Promoting Lived Experience leadership and engagement in mental health and wellbeing research and dissemination:

A scoping review

A custom report for the Victorian Collaborative Centre for Mental Health and Wellbeing, the Victorian Department of Health

The project team

The project was awarded to a team from Wellways Australia led by Dr Catherine Brasier (National Evaluation and Research Manager and Consumer Academic/Adjunct Research Fellow at La Trobe University). All members of the research team identify as Lived Experience. The team included consumer, carer, and First Nations expertise.

Project lead

Dr Catherine Brasier

National Evaluation and Research Manager – Lived Experience, Wellways Australia

Adjunct Research Fellow, Social Work and Social Policy,

Department of Community and Clinical Health,

School of Allied Health, Human Services and Sport

Project team

Jamie Lee Lalic

Reconciliation Action Plan (RAP) Officer, Wellways Australia

Anita Conlon

Lived Experience Coproduction and Engagement Coordinator, Lived Experience Leadership Team, Wellways Australia

Rowena Jonas

Practice Advisor Family Support, Lived Experience Leadership Team, Wellways Australia

Simon Katterl

Simon Katterl Consulting

Tessa Zirnsak

Research Fellow and Consumer Academic, Social Work and Social Policy,

Department of Community and Clinical Health, School of Allied Health, Human Services and Sport

Acknowledgements

We gratefully acknowledge the funding and support of the Victorian Collaborative Centre for Mental Health and Wellbeing. We would like to especially thank Katie Jones, Dean Kolovos, Ateeq Zaki and the Collaborative Centre's LEAP Research Strategy Working Group. We also acknowledge the kind support of Wellways Australia and La Trobe University. Special thank you to all of the people who responded to requests for publications and consultations.

A note about language

In this report we acknowledge that the language used to describe experiences of distress or providing support and caring in research is imperfect and that we are yet to land on terms which are universally accepted. The language used in some of the publications which have been included can be problematic, and do not reflect the views of the authors. It is important that consumer and carer, family and supporter conceptions of their experience, and their languaging of this is promoted moving forward.

In this report we used the terms "consumer" to indicate people who have the Lived Experience of distress, and "carer, family and supporter" to indicate people who have the Lived Experience of providing care and support; this languaging is consistent with current terminology used by the Collaborative Centre. We also use the language "Lived Experience" when we are more broadly discussing ideas that relate to both consumers and carer, family and supporters.

Suggested citation

Brasier, C., Zirnsak, T., Katterl, S., Jonas, R., Conlon, A, Lalic, J. "Promoting Lived Experience leadership and engagement in mental health and wellbeing research and dissemination:
A scoping review", The Victorian Collaborative Centre: Melbourne, 2023.

Executive summary

"Meaningful engagement means ensuring that people who are or have been impacted by an issue are involved in developing, implementing, and evaluating the effectiveness of strategies to address the issue." Ash and Otiende (2023)

Consumers, carers, family, and supporters are the experts in their own lives, yet they are often the subject of research, not the leaders of it. The Royal Commission into Victoria's Mental Health System documents countless firsthand experiences and feedback from consumer, carers, family, and supporters which detailed how they are not listened to, and how this has contributed to damaging experiences, human rights violations and poor outcomes. This sits against the backdrop of long-term advocacy for change from both the consumer-survivor movement (Epstein, 2013) and carers, family and supporters and their movement (Rising Together Action Group 2022, Schirmer, Mylek and Miranti 2022).

As a result, the Royal Commission has stated that consumers, carers, families, and supporters should be involved in every part of the mental health system including research. In recent years, Australian health policy has stated that people with Lived Experience should be included in research and evaluation (Australian Government Department of Health 2017, Australian Commission on Safety in Healthcare 2023, World Health Organisation 2023). Peer reviewed literature advocating for people with Lived Experience to be active drivers and producers of research goes back more than 20 years (Howard and el-Mallakh 2001) which indicates that the status quo has prevailed despite calls for co-ownership and new ways of doing things.

This project aims to identify the opportunities for the Victorian Collaborative Centre for Mental Health and Wellbeing, and the broader mental health and wellbeing system, to better promote Lived Experience Leadership and engagement in research and dissemination. This research emphasises the importance of democratising mental health and wellbeing research so that it can be shared and used by people in the community.

This project was comprised of a scoping review and community consultations. The scoping review drew on systematic review methods, plus hand searching, requests for publications and grey literature through professional and Lived Experience networks. In total 81 pieces of literature were identified. Fifty-one peer reviewed publications were identified from the database search (CINAHL and Medline), 13 peer reviewed publications were identified by handsearching and professional networks, plus 17 pieces of grey literature. This literature included a combination of Lived Experience-led and non-Lived Experience-led research. This review identified a dearth of publications specifically addressing carer, family, supporters as researchers; more targeted searches may be required to explore topics that may not be fully addressed here. The publications addressing consumers as researchers showed that often consumers are playing more peripheral roles in research, and that there is still much work to be done. There is extremely limited research addressing First Nations, CALD, LGBTIQA+ and other diverse communities.

We also consulted with a total of 23 people with Lived Experience, including research allies to explore this topic further and respond to significant gaps in the research. This included 8 consumers; 3 carer, family and supporters; 5 consumer leaders; 3 carer, family, supporter leaders; 1 First Nations carer; and 3 research and senior service delivery allies. Carers, family and supporters and consumers were offered the choice of attending a focus group or an individual interview. Two consumers chose the interview. All leaders were interviewed individually due to scheduling requirements. Several common themes arose between the groups including remuneration, power sharing/equality, developing a professional research career, having the right supports (training, mentoring, etc) and including the whole consumer and carer, family and supporter community. Limitations included a dearth of carer researcher literature, a lack of literature addressing mixed methods and quantitative research, and relatively few authors producing Lived Experience-led research. Strengths included that most of the publications were Australian, as were many of the Lived Experience authors. This suggests that Australian researchers are already committed to exploring how people with Lived Experience can lead and disseminate research, and that we have great access to people who are experts in this and have been peer review published (e.g., Cath Roper, Michelle Banfield, Indigo Daya, Vrinda Edan). Overall, each of the groups thought that people with Lived Experience should be driving research, and that this should be accessible to the community. Based on these findings, we have made the following recommendations:

Recommendation One: Organisations are underpinned by the principle ‘Nothing about us, without us’ – Leading with Lived Experience

Primary goal: To create a research culture that is Lived Experience centred and led.

Top 5 recommended actions

1. Develop a quality improvement tool to audit Lived Experience research and knowledge translation culture.

2. Create engagement opportunities which honours the diverse and sometimes conflicting experiences of consumers and carers (i.e. in research design - be intentional in creating safe places for both consumers and carers through separate and joint codesign sessions).

3. Create an online portal that shares accessible and easy to understand information using a range of mediums (e.g. art, video, interactive activities).

4. Establish a ‘Lived Experience Research Review Board’ to define and uphold the standard for a Lived Experience research, co-production and co-design.

5. Develop, implement and evaluate the tools, frameworks and guidelines to support people with Lived Experience including peer workers to lead, create and disseminate research.

Recommendation Two: Organisations create opportunities for people with Lived Experience, researchers and mental health services to work together to create effective knowledge translation

Primary goal: To bring together people from Lived Experience, research, peer work and mental health services to work together to create impactful knowledge translation.

Top 5 recommended actions

1. Create a Lived Experience Strategic Lead to develop knowledge translation relationships.

2. Create a ‘Lived Experience Research and Knowledge Translation Development Unit’ to support pipelines for research pathways including PhD and Masters by Research, plus early and mid-career researchers and peer worker researchers.

3. Create a dedicated ‘Lived Experience-led Knowledge Translation Network’.

4. Develop an ‘Allyship and Supporter Program’ for researchers wanting to improve their Allyship and Lived Experience capabilities.

5. Create a research and knowledge translation ‘Connectors Program’ to support partnership across Lived Experience, research, peer work and mental health services.

Recommendation Three: Create opportunities for people with Lived Experience to be contributors and leaders at every stage of the research life-cycle

Primary goal: Build a community of people who have Lived Experience (including peer workers) and would like to engage with research.

Top 5 recommended actions

1. Create opportunities for people with Lived Experience including peer workers should be actively participating in and driving research priorities. It should include a specific focus on carer, family and supporter researchers and peer workers.

2. Conduct fun and social activities that make research accessible and engaging to encourage community participation.

3. Organisations should create a dedicated 'Lived Experience Leadership Program' which focuses specifically on leadership capabilities for those working in knowledge translation including peer workers.

4. Develop and implement inclusive and accessible translational research practices.

5. Co-produce Lived Experience-oriented measurement tools and methods to better establish the impact of services and supports, as well as participant experience.

Recommendation Four: Bring together people with Lived Experience and key stakeholders to improve the outcomes that matter most to consumers, carers, family and supporters

Primary goal: To establish ways of working together that are safe, respectful and constructive.

Top 5 recommended actions

1. Develop Lived Experience-led wellbeing practices so that consumers and carers, family and supporters feel safe to participate. Include trauma-informed and flexible ways to work together.

2. Create a statement of 'Lived Experience Commitment' to outline how organisations will work with people who have Lived Experience on all projects and at all levels of the organisation.

3. Conduct a mentoring and support program for peer workers to develop and run Lived Experience research projects within their service.

4. Conduct networking and educational programs that increase the connection between Lived Experience, research and service delivery and development.

5. Create a Lived Experience dissemination program.

Recommendation Five: Action to support First Nations people and communities

Primary goal: Putting First Nations people and communities at the heart of social and emotional wellbeing.

Top 5 recommended actions

1. Create pathways and initiatives that support First Nations people to drive translational research.

2. Create dedicated First Nations Research and Knowledge Translation Leads who could co-ordinate First Nations teams and play a pivotal role in cementing organisation's culture around reconciliation and cultural safety.

3. Develop relationships with First Nations organisations and communities to create a ‘First Nations Action Plan’ that is culturally safe.

4. Develop and share information, resources and training to increase cultural safety for non-First Nations people working in research and knowledge translation.

5. A ‘First Nations Statement of Commitment’ should be developed; this should be First Nations-led and conducted.

Recommendation Six: Evaluate the impact of organisations that support Lived Experience leadership and involvement in research and dissemination

Primary goal: Identify the impact of organisations who promote Lived Experience leadership, creation and dissemination of research, and the outcomes important to this.

Top 5 recommended actions

1. Conduct formal Lived Experience-led evaluations of meetings, key activities, projects and services, as well as the organisations impact overall.

2. Evaluate the impact of projects and programs that promote Lived Experience people to lead, create and disseminate research and knowledge translation.

3. Collect and evaluate organisational data that establishes the degree of Lived Experience participation and employment in an organisation or project.

4. Evaluate targets relating to First Nations people’s engagement and leadership in oganisations against their commitments and policies.

5. Disseminate the findings of evaluations through a special report, in the Annual Report and other accessible platforms (e.g. YouTube video, organisations webpage).

To conclude, we have established the state of the literature and explored this topic through consultations. The Collaborative Centre can play a pivotal role in improving the real-world outcomes of consumers and carers, families, and supporters by centralising Lived Experience in mental health research. The Collaborative Centre should support people with Lived Experience, research skills and mental health organisations to find new ways to define and solve challenges together.

Scope

This project was commissioned by the Victorian Collaborative Centre for Mental Health and Wellbeing (herein the Collaborative Centre) on the 31st of August 2023. The Royal Commission into Victoria's Mental Health System (RCVMHS) recommended the establishment of the Victorian Collaborative Centre for Mental Health and Wellbeing to meet a gap in translational research into treatment, care and support for adults and older people. The Collaborative Centre will be the first of its kind in Australia and will contribute to Victoria's standing as a national and international leader in mental health and wellbeing.

The purpose of this project is to identify the opportunities for the Collaborative Centre and broader mental health and wellbeing system to better promote Lived Experience leadership and engagement in mental health and wellbeing research and dissemination. People with Lived Experience are needed to set new research agendas and help develop new theories and ways of knowing. Research that actively involves people with lived and living experience in all stages moves research from being done for people who have or are experiencing mental health challenges to being done with or by these groups and individuals. As set out in the Royal Commission report, Lived Experience-led research and evaluation is fundamental to an adaptive system. Whilst one of the strongest health consumer/carer, family and supporter movements has been in mental health, the active involvement of people with Lived Experience and incorporation of their knowledge into research and the health system is fragmented and de-prioritised, hampering effective implementation. The Collaborative Centre aims to promote exemplary practice in Lived Experience leadership and engagement in mental health and wellbeing research based on an intersectional, inclusive approach. It has a unique opportunity to 'lead the way' in creating opportunities for individuals who have faced significant barriers to participating in research to be involved in participatory research opportunities at every level and stage of research.

Table of Contents

Chapter One - Background

This report explores how the Victorian Collaborative Centre for Mental Health and Wellbeing could support people with Lived Experience to lead, create and disseminate research.

Please keep an eye open for summary boxes like this one. These will provide a quick snap shot of each sections key messages and help you navigate the report.

Introduction

This Chapter explores some of the background that can help us understand why it is important that people with Lived Experience lead and are active in research. Key points include:

- There is a growing interest in Lived Experience driven research and policy, yet there has been relatively little progress
- The systemic oppression of consumers and carers, family and supporters impacts on their engagement and leadership of research
- People with Lived Experience are impacted by the social determinants of health (e.g. marginalisation, unemployment, poverty, homelessness and isolation etc)
- The history of the consumer/survivor movement and rise of mad studies has challenged the role of people with Lived Experience in research
- Carer, family and supporters often feel overwhelmed and overlooked despite providing millions of dollars in unpaid care and brining a strong relational lens
- First Nations people's social and emotional wellbeing may also be impacted by social and systemic factors such as discrimination, grief and loss, economic and social disadvantage, family and community violence and incarceration

Later in this chapter we talk about recent policies that impact on Lived Experience people in research. We will also outline a few contemporary projects connect policy and Lived Experience people in research.

A long road – our Lived Experience journey from the Lunacy Act to the RCVMHS

Reflecting international trends, Australia has a growing interest in involving mental health consumers and carers, families, and supporters in research (Daya, Hamilton and Roper 2020, Jones, Atterbury et al. 2021, Maylea 2022). This includes Lived Experience-led research (Epstein 2013, Banfield, Morse et al. 2018, Banfield, Morse et al. 2018, Roper, Grey and Cadogan 2018, Edan, Sellick et al. 2021). However, this is complicated by social and cultural factors such as our history of disempowering consumers and carers, families, and supporters through systemic approaches such as institutionalised and coercive approaches care, and in contemporary practice the on-going legacy of “low expectations” about the future of people who have serious and on-going experience of distress as described in the RCVMHS (Royal Commission into Victoria's Mental Health System 2021). In Victoria, the Lunacy Act (1890) 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. Despite the abolition of asylums after the introduction of the 1986 Victorian Mental Health Act (State Government of Victoria 1986) and the 2014 Victorian Mental Health Act (State Government of Victoria 2014) that responded to lack of community support, images such as this continue to have a significant cultural impact and perpetuate the expectation that people who are 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 (Epstein 2013). These movements responded to the detrimental impact of institutionalisation, including the use of asylums, medicalisation and compulsory treatment (Rose 2017, Daya 2022). 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’ (Beresford and Russo 2021, World Health Organisation 2023). During this period psychiatrists and clinicians were seen as the experts, not consumers or carers, families and supporters. Consumer leaders also highlighted the lack of community supports available to people once the asylums closed (Ramon, Healy and Renouf 2007, Roberts and Boardman 2013). More recently there has been the introduction of Mad Studies abroad (Beresford & Russo, 2021; Rose, 2017), including international journals emerging from Australia (Sinclair et al., 2023). This discipline emerges from the Mad Community and seeks to challenge power structures inside and outside “the academy” (academic and formal knowledge-making institutions) (Armstrong and LeFrancois 2021), as well as providing a venue for mad-led knowledge to be shared (Sinclair et al., 2023).

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 (Alegría, NeMoyer et al. 2018). Social determinants such as poverty, marginalisation, social disconnection, impacts of colonisation and intergenerational trauma 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 the possibility that people who experience even intense or on-going challenges can also lead happy and successful lives (with or without “symptoms”) (Anthony 1993).

The RCVMHS 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 (Royal Commission into Victoria's Mental Health System 2021). Many of the witness statements described inadequate or unhelpful experiences with the mental health system resonating with the themes discussed in this section, as well as hope for a better future where consumers and carers, families and supporters hold the power to shape research and the mental health system.

Understanding mental health consumers

Australian mental health consumers experience a great diversity in mental health challenges which range in intensity and duration (ABS 2007). 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 (Productivity Commission 2020). People with Lived Experience also come with intersectional identities of privilege and oppression, including based on gender, disability, race, and whether they are Aboriginal and/or Torres Strait Islanders (Aboriginal and Torres Strait Islander Lived Experience Centre, 2020).

The RCVMHS 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 the failure to receive life changing support (Royal Commission into Victoria's Mental Health System 2020, Katterl, Lambert et al. 2023, Wellways Australia 2023). The RCVMHS acknowledged that consumers have been marginalised by a ‘broken’ mental health system and often experience high levels of marginalisation, unemployment, poverty, homelessness and isolation (Royal Commission into Victoria's Mental Health System 2020). Many consumers identify that they often cannot access services when they need them, but they continue to be left out of system design, research, or 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 change (Centre for Mental Health Learning 2019). Despite recent pushes from public policy, consumers do not generally play a major role in research, outside of being research participants (Royal Commission into Victoria's Mental Health System 2020). This may be due to power-imbalances between Lived and non-Lived Experience workforces and disciplines. The Royal Commission found:

> Complex power imbalances rooted in professional, historical, social and statutory hierarchies continue to influence the opportunities available for people with lived experience of mental illness or psychological distress to lead, shape and participate in Victoria's mental health system (State of Victoria, 2021, p. 18).

This may be due to several factors such as disruptions to education, feeling like they do not belong in these environments (Edan et al., 2021), or because researchers do not identify as Lived Experience or work from that perspective.

Understanding mental health carers, family, and supporters

It is estimated that there are more than 736,000 mental health carers, families, and supporters in Victoria who give their time, effort, and love to care for and support a family member or friend with a mental health challenges or mental distress. Carers, families, and supporters contribute billions in unpaid work to the Australian economy (Deloitte's 2021) and often experience poorer health outcomes. Australia's National Carer Wellbeing Survey 2022 indicated that mental health carers, families and supporters have poorer outcomes than carers in general and they report being impacted by stigma (Schirmer, Mylek and Miranti 2022). Since the deinstitutionalisation of the Victorian mental health system carers, family and supporters report that they have not been adequately supported to provide care, receiving little support, education or resourcing to do the work (Royal Commission into Victoria's Mental Health System 2021). When families get the right support early and continuously, the social impact benefits flow through to the people they support, their wider families and their communities. Many carers, family and supporters 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 (Wyder, Barratt et al. 2021).

Since the RCVMHS (Royal Commission into Victoria's Mental Health System 2021), the Victorian State Government has increased the involvement of carers, family and supporters within mental health system reform to drive change although this is still deeply insufficient. The family carer workforce is undergoing rapid change and has typically been an underdeveloped and underutilised part of the peer workforce (Centre for Mental Health Learning 2019, Centre for Mental Health Learning 2019). The carer, family and supporter workforce need support to find solutions to support families better and to facilitate meaningful change across the sector.

Exploring voices and experiences of people from diverse backgrounds

People from diverse backgrounds are often underrepresented in mental health research and service design and delivery (Productivity Commission 2019). In this report when we refer to “diverse backgrounds” we are referring to people from culturally and linguistically diverse communities (CALD), LGBTIQ+ people and people with disability, as well as young people and older people. Victoria’s ‘Diverse Communities Mental Health and Wellbeing Framework and Blueprint’ (Victorian Government 2023) 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
- Experince 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 unwell in the first place

First Nations people and communities

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 (Australian Government Department of Health 2017). This has been linked to stressors such as discrimination, racism and social exclusion, grief and loss, removal of children, economic and social disadvantage, family and community violence, incarceration, substance use and physical health problems (Australian Government Department of Health 2017). Despite this First Nations people often lack representation in research and service development and delivery. NGOs such as Wellways have led the way by implimenting Frist Nations specific innovations such as a dedicated Reconcilliation Action Plan Officer who leads the First Nations Caucus and First Nations Retreat.

Summary of recent policies which impact on Lived Experience and research

The importance of including people in policy and research has been emphasised in Australian and international policy for many years, despite this there has been little progress. Often Lived Experience “inclusion” in policy is token and poorly described.

Lived Experience participation and leadership has been encouraged by International and Australian policies for many years but is yet to be routinely implemented (Rose, Carr and Beresford 2018, Sangill, Buus et al. 2019). Until recently Australian mental health policy has almost exclusively focused of the provision of mental health services (Productivity Commission 2020). Increasingly, policy documents refer to the importance of Lived Experience in developing policy and services, although this is often vaguely reported or done by consultation and may be token; this is a lost opportunity as it fails to recognise how the leadership of consumers and carers, family and supporters 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 (Australian Government Department of Health 2017). It recommends the “National Mental Health Commission to work in collaboration with the National Health and Medical Research Council, consumers and carers, families and supporters, states and territories, research funding bodies and prominent researchers to develop a research strategy to drive better treatment outcomes across the mental health sector” (Australian Government Department of Health 2017). 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 carers, families and supporters should be partnered with in the planning and decision making.

The Productivity Commission’s ‘Inquiry into Mental Health’ (Productivity Commission 2019) 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 carers, families and supporters 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) (Productivity Commission 2020). This includes considerations around quantitative and longitudinal research. The Commission suggested eight principles: That research is i) fit for purpose; ii) maintains social licence; iii) supports continuous improvement; iv) has independence; v) transparent; vi) person centred; vii) culturally capable; and viii) generates a net value.

Summary of key research projects that intersect with Lived Experience and policy

Innovations such as the ‘ALIVE Centre’ (University of Melbourne) uses a Co-Directorship model with Sandra Eades, Michelle Banfield, and Victoria Palmer. The ALIVE Centre brings together researchers, health professionals, people with Lived Experience of mental distress and carers, families, and supporters to create new solutions. The Independent Advisory Board, the Intersectoral Committee and the International Scientific Committee are each co-chaired separate teams of four people with Lived Experience (two consumers and two carers). Dedicated parts of the project are consumer-led, including the NextGen Network and Co-design labs (https://alivenetwork.com.au/). The ALIVE project is discussed in point 2 of the Australian 'National Suicide Prevention Advisors Final Advice' (Commonwealth of Australia 2021) and is a good example of innovations which connect Lived Experience research and policy.

Similarly, the 'Equally Well' project bought together more than 90 organisations alongside people who have Lived Experience (Mitchell Institute 2022). This collective impact strategy aims to improve the physical health of people living with mental distress at a national, state and territory, and regional level. Originally supported by the National Mental Health Commission, then the Australian Government Department of Health and Aged Care, the project completed consultations to inform the Equally Well National Consensus Statement. Equally Well was a priority action (Action 14) of the 'Fifth National Mental Health and Suicide Prevention Plan' which states that the Australian Government will improve the physical health of people who experience distress (Australian Government Department of Health 2017). While the Equally Well program incorporates Lived Experience, it still predominantly focuses on the perspectives of mental health service staff and researchers more broadly.

The Centre for Mental Health Nursing (CMHN) led by Associate Professor Bridget Hamilton, and their ongoing Consumer Academic Program, led by Vrinda Edan, provide an excellent example of consumer-led and interdisciplinary research projects. CMHN seek to advance the science and art of mental health nursing by cocreating system and practice change with people with Lived Experience of mental health service use their families/carers and other professions (Centre for Mental Health Nursing, 2023). CMHN leads on consumer-led and interdisciplinary research projects, developing research on alternatives to the use of force and on mental health care in inpatient environments. Underpinning this work are a series of principles that serve priorities of sustainability of the CMHN, 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 (Centre for Mental Health Nursing, 2023).

Summary of government policies addressing partnering with consumers

Both international and Australian (Australian Commission on Safety in Healthcare 2023) health policies are increasingly stating that they want to partner with consumers and carers, families and supporters to deliver services. There is also increased emphasis on creating systems that are designed and used to support health consumers and carers, families and supporters to be partners in healthcare planning, design, measurement and evaluation (Australian Commission on Safety in Healthcare 2023); this includes measuring patient experience and the use of self-reported measures instead of clinician reported measures (e.g. HoNOS).

Consumer advisor perspective

The current policy landscape is high on aspiration and statement, low on material commitments and mechanisms for impact. There are not for example, concrete policies that give effect to international obligations under Article 4(3) of the Convention on the Rights of Persons with Disabilities, which requires consultation with people with disabilities and their representative organisations. There are few policies that require certain forms of Lived Experience leadership and engagement at different levels, and fewer enforcement mechanisms to give effect to that. As the research in this paper will show, there are significant and enduring power imbalances that limit the systems' ability to realise a truly different system, including one based on innovative research. Change will require robust policies with reporting and enforcement mechanisms that drive real culture change.

Conclusion

Despite this complex history, recent developments in Australian policy and practice (Productivity Commission 2019, Royal Commission into Victoria's Mental Health System 2021) have attempted to resituate consumers and carers, families, and supporters in the center of every level of the mental health system including research; this is an interesting challenge considering our history of denying the power and expertise of consumers and carers, families, and supporters. It also raises questions about underlying factors that could replicate new forms of inequity or power-differences and prevent consumers and carers from thriving in the ultra-competitive “publish or perish” culture of the academic system.

Chapter Two - Project aims and methodology

Chapter Two talks about the methods that we used to explore how people with Lived Experience can be involved in the leadership, creation and dissemination of research. This project provides a snapshot of research on this topic and is a part of a larger series of work. Further exploration is recommended using more targeted methods.

This rapid scoping review included:

- A structured review
- Grey literature review search
- Consultations and focus groups
- Hand searching
- Requests for publications through professional networks

Introduction

This chapter outlines the methodology used in this report. This project was comprised of a rapid scoping review and community consultations. The review drew on systematic review methods, plus hand searching, requests for publications and grey literature through professional and Lived Experience networks. The community consultations included consumers, carers, family and supporters, Lived Experience leaders and research and senior management allies.

Project aim

This project aims to identify the opportunities for the Collaborative Centre and broader mental health and wellbeing system to better promote Lived Experience leadership and engagement in mental health and wellbeing research and dissemination.

Key research themes and questions

We used consultations and a rapid scoping literature review to explore:

- What are the barriers and enablers?
- What does good effective and active involvement look like?
- How do we build research capacity?
- What other opportunities could the Victorian Collaborative Centre support to Lived Experience knowledge translation, dissemination and increase research capacity?

Review methods

This review was comprised of a structured review which used a search method similar to those used in systematic review. To allow for greater flexibility it also included hand searching and requesting for publications through LinkedIn and team members' professional networks. To assist in hand searching we used the Lived Experience Digital Library (https://livedexperiencedigitallibrary.org.au/browse-library/lived-experience-research).

Structured review method

Our search was conducted on CINAHL and MEDLINE databases on 15 September 2023. Our search strategy (including key words and MeSH terms) was chosen to reflect the key aims of the tender using the Population, Concept, and Context model of literature search recommended for scoping reviews:

Population:

P –Lived Experience of mental distress or carers, family, and supporters

C – Concepts: Leadership and engagement

C – Context: Mental health

The key words that were used are detailed below in the Appendix.

Criteria

Publications were included if they addressed how people with the Lived Experience of mental distress and/or carers, family and supporters could create, lead, or disseminate research. Peer reviewed and grey literature was included.

Publications were excluded if: i) people with Lived Experience were included only as research participants; iii) it did not explicitly address research or researchers; iii) it was not specific to the Lived Experience of mental distress or carers, family, and supporters. Thesis, opinion, commentary, books and publications which did not have a full text were also excluded.

Search process

The search was conducted on each of the databases. It was then exported to Endnote where it was screened by title (CB, TZ). Next it was imported in to Covidence (www. Covidence.org) where the publications were screened by two reviewers at each stage (CB, TX, AC) – abstract and full text. Meetings were held and conflicts were decided unanimously (CB, TX, AC). A member of the Collaborative literature Centre (KJ) acted as a tie breaker, if required.

Grey literature review method

In this review grey literature was collected through multiple avenues: i) the investigators posted requests for information on LinkedIn; ii) the investigators emailed people in their professional networks to request information; iii) further literature was recommended during the consultations; iv) Google and website searches were conducted. Grey literature was screened by using the same processes and inclusion/exclusion criteria used for peer reviewed literature.

Consultation methods

The total number of participants in focus groups/interview is expected to be between around 20 people, plus feedback from professional networks. Consumers and carers, families and supporters were able to attend either the focus group or a one-on-one interview. Our consultation method is comprised of:

1) three focus groups; 1 consumer and 1 carer, family, and supporter, 1 First Nations focus group, plus supplementary interviews
2) interviews with Lived Experience Leaders and research allies
3) on-going frequent engagement with professional networks (feedback through Linked In, Twitter, Wellways networks, email, networks etc).

The specific methods are detailed below.

CONSUMER FOCUS GROUP: A range of consumer Lived Experience including people from the community, peer workers and Lived Experience professionals.

CARER, FAMILY AND SUPPORTER FOCUS GROUP: A range of carer, family and supporters from the community, peer workers and Lived Experience professionals.

FIRST NATIONS FOCUS GROUP: All members of the First Nations dedicated focus group will be First Nations participants. This will be led by Jamie Lee (Wellways Reconciliation Action Plan leader). This will include First Nations carers, community members and First Nations staff from Wellways.

LIVED EXPERIENCE LEADERS’ INTERVIEWS: Will consist of interviews with key consumer, carer, family, and supporters who hold significant leadership roles in the community or professionally, including as researchers.

ALLY INTERVIEWS: Will consist of interviews with key research allies who have senior research or service delivery roles, and who actively engage in and support Lived Experience research.

Development of consultation material

All consultation materials and processes including the interview schedule, comfort and choice statement and acknowledgements were reviewed by the research team. Jamie Lee reviewed these for cultural safety, and they were further customised for the First Nations focus group. The timing of the First Nations groups was extended after consultation with Jamie Lee due to its close timing with the Voice Referendum in October 2023.

Extraction, analysis, and synthesis

Each of the publications was extracted into a custom spreadsheet. The research questions were then used as the basis of a deductive framework. Material from the publications which answered these research questions was summarised and then synthesised. This synthesis was contextualised within the publications included in this review as well as with border material.

Team processes – collaboration, power sharing and challenges

The Lived Experience project team met fortnightly for the duration of the project and had regular email correspondence. The project team and key staff met with the Collaborative Centre every fortnight to discuss feedback, share learnings and suggestions. Regular updates and results were shared as promptly as possible with the Lived Experience team and Collaborative Centre team. All Lived Experience team members were able to provide feedback and suggestions before the reports were finalised.

This project tried to optimise the amount of Lived Experience contribution. Group reflection noted that there were several limitations due to the rapidness of the review (11 weeks), small number of carer, family and supporter team members and the prescriptive nature of a structured review. Updates via video and over Zoom were made to the Collaborative Centre's LEAP Research Strategy Working Group. The Plain Language Statement was circulated to consultation participants once it was confirmed, and ahead of publication. While there is strong evidence of Lived Experience contributions in this project, further exploration using co-production methods is recommended. This is a part of a larger project.

Conclusion

This section described how the literature review and consultations were conducted. This includes a description of power sharing and collaborative tools used by the team.

Chapter Three – Results: Scoping review

Chapter Three reports the findings that relate to the rapid scoping review. Chapter Four reports on the findings of the consultations.

In total we identified 81 pieces of literature that addressed the 'Research themes and questions' listed in Chapter Two. This included 64 articles from peer reviewed database and hand searching. 17 pieces of grey literature were also identified.

Introduction

This section reports on the results of the review including the structured review (including hand searching and publications sought through professional networks) for both peer reviewed and grey literature.

What is a peer reviewed article?

A peer reviewed article is a way of sharing (or "disseminating") scientific and research findings. It is called "peer" reviewed because it must be approved for publication by two other experts in that topic as well as the editor of the journal. These journals are collected and kept in databases.

Rehabilitation psychiatry

AUSTRALASIAN PSYCHIATRY

Constructing recovery: A Lived Experience and post-structuralist exploration of how the meaning of personal recovery and rehabilitation has changed over time

Sage

Catherine Brasier

Lisa Brophy

Carol Harvey

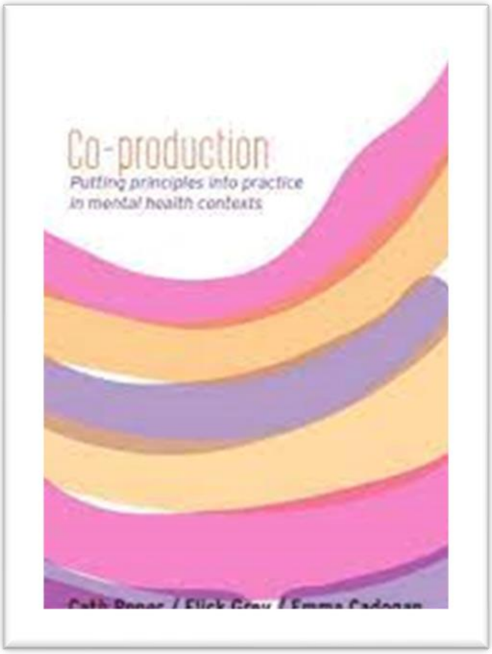
Abstract

Keywords:

If you are a career researcher, sharing the results of your research in this way is a key requirement of your job. But if you are a general member of the community you might not even be able to access them. Researchers wanting to publish in "Open Access" so that anyone can read their article can expect to pay upwards of $4,000 to do so.

Hot tip: you can contact the lead author of peer reviewed articles. Their email is listed on the publication and they usually appreciate the interest. You can check and see if they can send you copies of their articles.

Ok, so what is grey literature then?



Grey literature is any publication that has not been published by peer review (e.g. Government or industry reports). It is often not collected in reviews as it can be seen as lacking objective verification (i.e. peer reviewed). However, for some review topics the inclusion of grey literature is essential. Grey literature can provide information about how services, government and not-for-profits respond to important practical topics such as service provision and research. It is also a key source of Lived Experience oriented research frameworks and guidelines.

Hot tip: Government and organisational websites are an excellent source of grey literature. And so is “Professor Google” 😉

PRISMA chart

This PRISMA chart shows the number of publications included and excluded at each stage of the review.

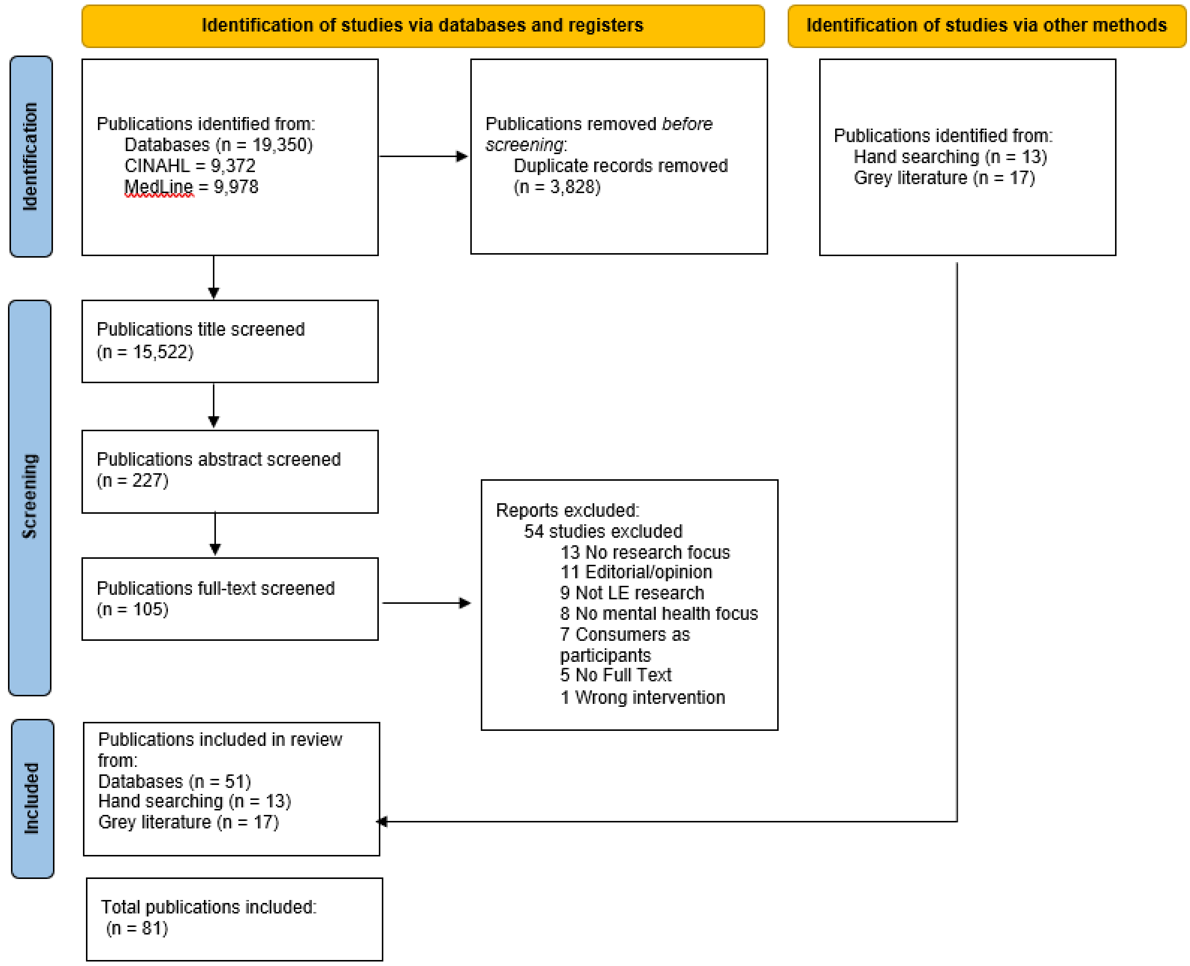


Figure 1. The flow of publications through the review

Structured review

The following section presents all peer reviewed articles that were identified from the structured review, including hand searching and papers collected from our professional networks.

Key findings from the peer reviewed literature included:

- The peer reviewed papers were from Australia, Canada, Denmark, Norway, the Netherlands, Slovenia, UK and US. Australia was the highest contributor of publications
- The most common type of paper was qualitative research. In contrast there was only 2 quantitative papers
- The publications addressed topics such as the epistemology of Lived Experience research, the role of peer researchers, co-creation, co-production and co-design, consumer and carer, family supporter researchers working together, power, effective advisory groups, researcher allyship, academia, training Lived Experience researchers and young people as researchers

See the Appendix for a complete list of the included peer reviewed publications. Information regarding the level of Lived Experience involvement in each publication should be considered *indicative* as extraction was expediated and this information may be hard to locate or poorly reported.

Results – Grey literature

This section presents the findings from the grey literature search. A reminder that the information regarding the level of Lived Experience involvement in each publication should be considered *indicative* as this information is often hard to locate or is poorly reported.

The last section briefly reported on the peer reviewed articles identified by this review. The following section tells us more about the publications from the grey literature.

Key messages from the grey literature included:

- All the grey literature identified in this review is from Australia. Further information could be gained by exploring international sources
- The importance of active decision-making, Lived Experience-led research and co-production
- Overall, this review contained little information about working with First Nations. The grey literature included “Keeping research on track: A

companion document to ethical conduct in research with Aboriginal and Torres Strait Islander People and communities" which echoed many themes about trust and relationships, working with the community and building First Nations research capabilities that comes up in our First Nation consultation.

- We are all experts in our own lives!

See the Appendix for a complete list of the included grey literature publications.

Conclusion

This chapter has reported the results of the peer reviewed and grey literature search. It has demonstrated that there is a lively discussion about how people with Lived Experience could lead, create and disseminate research.

Chapter Four – Results from the consultations

Chapter Four hopes to address some of the gaps evident in the literature review. More comprehensive local consultations should be conducted, these should be considered a preliminary snapshot.

We consulted with:

8 consumers
5 consumer leaders
3 carer/family/supporters
3 carer/family/supporter leaders
1 First Nations carer/family/supporter/kin
3 senior research/service allies

Introduction

This section reports on the consultations. These findings are synthesised with the literature review findings in Chapter Five. All data collection was completed by people with Lived Experience. The First Nations consultation was facilitated by a First Nations project investigator (JLL).

Participants

Interviews were conducted from Friday the 27th of October to Friday the 3rd of November. The consumer focus group was conducted on Friday the 27th of October 2023 from 10:30am to 12pm. The carer, family and supporter focus group was conducted on Monday the 30th of October from 1pm to 2:30pm. The First Nations focus groups/consultations were conducted on in November 2023. The number of participants for each research activity is reported below.

Table 1. The number of participants that completed each research activity.

Participant Group	Number attended focus group	Number interviewed
Consumers	6	2
Carers, family, and supporters	3	-
Lived Experience consumer leaders	-	5
Lived Experience carer, family, and supporter leaders	-	3
Research allies		3
First Nations carer		1
Total	9	14

The findings of the consultations

The following Tables report the key points that came out of the focus groups and interviews according to the key themes of this research project (i. barriers and enablers; ii. good effective and active involvement; iii. research capacity building; and iv. future opportunities).

Consumers

The following section presents the key points that arose from the consumer focus group and interviews.

Hot tip: In this chapter there will be a brief summary at the start of each results table!

Key messages included:

- Systemic and institutional barriers for engagement and leadership
- The richness and diversity of our Lived Experience community, and the importance of our history
- Formal research pathways are essential, as well as other ways of contributing
- Increasing research skills and capabilities is essential
- People with Lived Experience can play many roles in research from Lived Experience-led, research assistant or as a community supporter etc
- Consumers care about research but often do not know how to get involved

Table 2. Summary of the key points from the consumer focus groups.

Consumers (n= 8)	
Theme One: Barriers and enablers *“We don’t have really good mechanisms for service evaluation that really capture people’s experiences.”* – Consumer participant *“Plain language summary, something that is very accessible, I love pictures, you know diagrams are really easy, and that are easy to share.”*- Consumer participant	
BARRIERS	ENABLERS
Systemic and institutional barriers to Lived Experience leadership and engagement in research (e.g., must have a PhD and track record for most top grants)	Both formal research (e.g. focus groups, surveys) and accessible options for involvement (e.g. art, yarning)
Barriers to developing a track record for career Lived Experience researchers include not being included as authors on peer reviewed papers	Recognising the richness and diversity of the Lived Experience community e.g., from Lived Experience-led research, the peer/Lived Experience workforce, to people in the community who are impacted by mental distress or service use
Not creating spaces that feel safe (e.g. not culturally safe, not providing options for consumers and carers, family and supporters to discuss things separately) or are trauma informed (e.g. lack of debriefing)	Fostering relationships and a sense of safety and trust
Not addressing power differentials	Being clear and transparent, acknowledging power between all members of the research team
We are not sufficiently making connections between the consumer Lived Experience workforce and research	The consumer Lived Experience workforce could be engaged to support Lived Experience research
We struggle to engage and connect with Lived Experience in the community, and to capture people’s real-life experiences	Being thoughtful about what kind of roles consumers can play in a research project. Is their experience a good match? What do they need to feel safe and included (e.g., accessibility)

Lack of peer supervision for Lived Experience researchers	Inviting consumers to be a part of research that is also meaningful and has a benefit for them
Lack of connection across important partners e.g., Primary Health Networks, Local Health Districts and Area Mental Health Services	Being connected to the Lived Experience community was experienced as helpful
Structural issues such as funding, remuneration, and casual employment	Valuing the perspective of people who do not have research training, recognising that they have a fresh perspective and bring lots of relevant knowledge and experience (i.e., citizen scientist etc)
Significant requirements around PhD participation/completion	Using language that is easy to understand and creating a way to communicate and share
Skills gaps e.g., finding and applying for funding and grants, and setting up research projects	Getting the right people in the room, to do this you need someone who knows the community
Lived Experience research is not always valued as much as non-Lived Experience research, it can be disregarded and seen as opinion or "not generalisable", especially if it does not use "rigorous" empirical methods	Increased allyship – active support for people with Lived Experience
People without research experience, qualifications and an academic track record are often ineligible or unlikely to be awarded competitive grants or may be limited to being an "AI" associate investigator (the lowest level of investigator)	Institutions provide support in the writing of grants
Theme Two: What does good effective and active involvement look like? *"Involving people at the very beginning, conceptualising the research and what even the topics are, the priorities should be coming from Lived Experience."* – Consumer participant	
Remunerated appropriately, not being underpaid, or paid using gift cards	
Lack of Lived Experience workforce forums to share and generate research ideas. The Carer, family and supporter workforce have a Lived Experience workforce forum, consumers could create something similar	
The importance of defining what we mean by "Leadership". Is this attributed by role title or should it be earned by commitment, knowledge and service to the Lived Experience social movement and values.	
Working with the Peak Bodies and other key partners, including university partners	

Utilising Peak Body (Tandem, VMIAC, SHARC) and organisational consumer lists, registers, and newsletters to connect to consumers
Connecting to consumers of the future and their friends and the broader community
Creating opportunities to challenge or create new forms of ‘evidence’ that reflects what consumers experience – not limiting that experience into biomedical or research constructions
Letting research participants and research team members know the results of the study, what impact it had and what it led to
Increased access to publishing and accessing peer reviewed information
Involve people in the whole research process, from the start of determining the research problem
Theme Three: Research capacity building *"Researchers giving time to budding Lived Experience researchers like myself, um to do that. That was so valuable, made me feel like it was an achievable goal rather than an aspirational thing”* – Consumer participant
Opportunities for PhD and Masters by research, plus mentorship where researchers give time and share skills
Developing capacity and opportunities for Lived Experience and non-Lived Experience researchers to come together to conceptualise important topics and set research priorities
Funding research projects that also help the Lived Experience/peer workforce achieve practical goals like having a union
Support increased funding opportunities by working with key funders (NHMRC, MRFF etc) to further extend Lived Experience as a standard requirement and increased power of Lived Experience (e.g., assessment criteria, assessment panel, addressing decision making power)
Communication through forums, facilitated groups, conferences and symposiums
There needs to be capacity building around new ways of understanding, exploring, and sharing – quantitative research does not show the full impact by itself
Peer researchers are embedded in many teams now – training, CoP for these researchers is a gap and could further build their research capacity

Theme Four: Future opportunities *“The VCCMH in its research and service partnerships, could do a lot to embed and model an alternative approach – through requirements and criteria for funding/inclusion and in developing fresh models for sharing research with the Lived and Living Experience Workforce and people with Lived and Living Experience and the community more broadly.” - Consumer participant* *“What is the impact that it (research) is having on their day-to-day life or wellbeing, and how is that relevant to them. Yeah, is good to communicate with people but also like it also depends what the information is.”* - Consumer participant
The Collaborative Centre should communicate to community, beyond professional spaces – “this is who we are, what we are about”
The role of the Collaborative Centre Clearinghouse is important in promoting access to research and information
Facilitating a two-way conversation between Lived Experience and research to support meaningful engagement
Sharing of approaches between participatory methods and research methods, to learn from both cultures
Approaching research in an accessible and democratic way by involving people who do not usually get invited into the conversation
Bridge gaps of understanding between what Lived Experience knows, and what researchers know so both sides can increase their understanding
There should be a focus on including people with Lived Experience who are not necessarily researchers in the research process, and not just as sources of information/data i.e., direct current service users, past service users, LEAGs and LEAPs, community forums etc.
Other ways of knowing beyond academic research – Lived Experience story-driven methods could be validated
Complete project and activities that explain how academic findings are translated into real-world research and what this means for people with Lived Experience
Mental health system factors should be a top priority (e.g. service barriers, wait lists, lack of access)
The Lived Experience community should be research agenda-setting and tackling exclusion
We need to scope everyday people (consumers, carers, families and supporters and the community) to see what they are interested in knowing and how they would like that shared with them
The role of Lived Experience people in leading “Needs Analysis” projects to detail and report on mental health service gaps should be explored

Connecting to the broader community and those who are not connected to mental health services, including hard to reach consumers
Support connection between consumers, carers, family, and supporters, the community, and researchers. Increase opportunities to share and understand each other by creating connection pathways and loops.
Create multiple ways to connect and share information (e.g., peer reviewed publications, YouTube, visual diagrams, and artwork)
Create accessible material that is easy to understand and share.
Utilise methods that are welcoming to people from CALD, First Nations, LGBTIQA+, neurologically diverse and disability.
Focus on Carer workforces research, as so little has been researched about that workforce
Validate research methods that centre story sharing

Carers, family, and supporters

The following section presents the key points that arose from the carer, family and supporters focus group.

Key messages included:

- The importance of relational approaches
- The impact of neo-liberal and medical models
- Carers would like to be a part of an on-going conversation and have flexible ways of contributing
- Support such as debriefs, study updates and mentoring

Table 3. Summary of the key points from the carer, family and supporter focus groups.

Carers, family, and supporters (n = 3)	
Theme One: Barriers and enabler *"Share the good news stories, what did we do, why does it matter?"* - Carer, family, supporter participant	
BARRIERS	ENABLERS
Lack of appropriate remuneration and pay	Being a part of an on-going conversation and connection as well as more casual opportunities
What do we mean by Lived Experience? Everyone has life experience, what is special about what we mean?	Recognition that the Lived Experience of caring is valued
Bureaucratic processes and the impact of neo-Liberal systems which focus on the individual not the broader social context (e.g. transactional vs person centred, individualistic vs community/mob focused, economic cost vs emotional cost to the person)	Having great support and including access to debriefs

<table>
<tr><td></td><td>Human rights focused</td></tr>
<tr><td colspan="2">Theme Two: What does good effective and active involvement look like?
“I have found giving actual financial incentives actually incentivises people to share their stories” – Carer, family, supporter participant</td></tr>
<tr><td colspan="2">Ending the study well by sharing an executive summary or the results of the study (without carers, family and supporters having to ask or follow up)</td></tr>
<tr><td colspan="2">Driven by carer, family and supporter and consumer need – and not just clinical interests</td></tr>
<tr><td colspan="2">Different modes of communicating e.g., website, mailing list, summaries, regular in person check-ins.</td></tr>
<tr><td colspan="2">Having information and updates distributed about the research project at many stages.</td></tr>
<tr><td colspan="2">Making the process accessible and inviting to the community. Why? What? How?</td></tr>
<tr><td colspan="2">Registers to keep people easily updated with information and research opportunities</td></tr>
<tr><td colspan="2">Theme Three: Research capacity building</td></tr>
<tr><td colspan="2">Increase access to summaries of recent research (e.g., Plain Language Summaries, video, audio, graphics)</td></tr>
<tr><td colspan="2">Support opportunities to lead or co-lead well-resourced projects</td></tr>
<tr><td colspan="2">Theme Four: Future opportunities
“Articulate the ‘why’, um I think that is really helpful, um then you can connect people with the passion for wanting change, to be part of change or to tell their story” – Carer, family, supporter participant</td></tr>
<tr><td colspan="2">Develop and disseminate Plain Language Summaries, video, audio, graphic information which are accessible (disability, visual, hearing, neurodiversity, CALD, First Nations)</td></tr>
<tr><td colspan="2">Partner with peak organisations and networks to promote to Lived Experience</td></tr>
<tr><td colspan="2">Develop grants program to encourage new research</td></tr>
<tr><td colspan="2">Set up a registry for people who would like to be involved in research activities</td></tr>
<tr><td colspan="2">Schedule conferences to educate people about the opportunities, share ideas and network</td></tr>
<tr><td colspan="2">Set up co-design advisory groups for all new projects</td></tr>
<tr><td colspan="2">Establish a reputation for research – improving access for information and discussion</td></tr>
</table>

Lived Experience Leaders

The following section presents the key points that arose from the consumer and carer, family, and supporter leader interviews.

Key messages included:

- Bureaucratic, biomedical and neo-liberal influences impact on relational experiences and related research
- Carers, family and supporters often feel left out of the process but are interested in flexible ways of engaging
- Would like to be included in the research process more fully (e.g. receive Executive summaries, updates, plain language summaries etc)
- The importance of making sure all voices are included and valued
- There are few carer, family, and supporter researchers in Victoria
- Sharing the wins is important
- Safe and fair participation (e.g. power differentials, remuneration, flexible participation options)

Table 4. Summary of the key points from Lived Experience leaders.

Lived Experience Leaders - Consumer (n = 5) and Carer, family, supporter (n = 3)	
Theme One: Barriers and enablers *“I find myself – this (reading academic literature) is too difficult, this is too hard”* – Industry Lived Experience Leader	
BARRIERS	ENABLERS
Carers, family, and supporters have significant caring responsibilities and unpaid labour precludes from involvement in workforce	Whole government response to change how we think about mental health, wider cultural change, not just biomedical
Bias towards certain research perspectives – the money comes to so-called ‘gold standard’ approaches such as biomedical research	Being supported as a peer researcher, surrounded by the right people, being asked about how to proceed with research
Not acknowledging differences and conflicts between consumer and carer experiences/perspectives	Around 60% of carers, families and supporters are also mental health service users, how would we like to work with these dual experiences?
Past experiences need to be acknowledged of feeling unsafe and unappreciated.	All voices are respected, making room for and supporting emerging or community voices
Carers, families, and supporters can feel like 2nd class citizens compared to consumers or not included or considered in research agendas	Easily accessible - Basic facts sheets & glossaries
Impact of expediated timelines and the reform process and system change needs to be addressed	Co-designing the translation of documents and material so they can be understood by the Lived Experience community
Language is inaccessible and too academic	Recognising the importance of relational work to many carers, family, and supporters
Carer, family, supporter research often lacks investment	Carer, family, and supporter researchers are excluded from participation due to education barriers, no access to higher education, lack of visibility, and battling to get into the academy

People may not identify as “carers”, especially young carers, family, and supporters	Courage to try something new and to do so risk failure
Biomedical and health products are valued more	Good experiences as a peer researcher makes sure people stay practicing research
People can be hesitant to recruit mental health service users	Mental health services are often overlooked, they are important partners in Lived Experience research
The reality of completing a PhD and having a research career (e.g., competitive, pressure, unstable career, sacrifice, stress, qualification dependant, etc)	Role modelling skills, partnerships and capacity all help develop Lived Experience Research
Theme Two: What does good effective and active involvement look like? *“Universities and services often don’t value the way we define research problems…. Defining the research problem is a great first step.”* - Lived Experience Carer Leader	
Utilising co-design methodologies and other Lived Experience-oriented research methodologies applied to the whole research project	
Have full authority, not just tokenistic consultation	
Practicing power sharing between researchers and community	
Collaborate in an outcomes-focussed way – providing a space for frank and collaborative discussions	
Strengths-oriented sharing “share the good news stories, what did we do, what does it matter?”	
Increasing conceptual competency and empowerment	
Strong communication so people see the impact research can have	
Allow people with Lived Experience to develop their own practice - not “capturing” Lived Experience. Capturing occurs when other disciplines or paradigms takes a Lived Experience concept or practice and claims it as their own (e.g. recovery oriented-practice)	
Support the growth of grass roots and community research, and intersectional work	
Always ask “who's missing from the room; who is asking the question; who's holding the power and authority?”	
Having choice about contributing, people do not always want to be the leader, work can be co-produced, co-led or led.	
The importance of leading or co-leading with clinical to impact real world outcomes e.g., interventions and service delivery	

Presenting at conferences could have benefit for Lived Experience presenters, and gave many first-time presenters an important opportunity
Theme Three: Research capacity building *"I love data!"* – Lived Experience Consumer Leader
Developing new ways to research the consumer journeys
Finding good ways to measure Lived Experience-oriented outcomes e.g., personal recovery, community connections, hope
Leading with Lived Experience researchers and recruiting Lived Experience people
Creating a bridge between Lived Experience and research – working together – e.g., Engaging in listening processes - acknowledging differences between consumer and carer
Supporting researchers to form relationships and partnerships with the Lived Experience community, they often do not know how to do this
Capability building around building strong partnerships and working collaboratively with people who have a different or conflicting point of view
Strong models already exist – that use a co-design approach and build research capacity
Challenges and opportunities in having a research career (PhDs, research students, supervisors, and teachers)
Involve community in data collection, the community needs to be involved
Explore options for higher education for people locked out of the education system
Need more consumer and carer, family, and supporter researchers. There are particularly few carer, family, and supporter researchers.
Mentoring and training, increased opportunities to explore and be a part of research
Creating opportunities to hear from Lived Experience researchers about the power they have to change things
Exploring Lived Experience values and practices within research
Theme Four: Future opportunities *"Fighting the fear that no good change is happening"* – Lived Experience Carer Leader
Lived Experience oriented research into service delivery should include ED alternatives and Lived Experience models, as well as preventative early intervention and post-discharge supports
Establish networks where all researchers, not just academic can learn about ethics, writing up research, and other researchers

Promoting underutilised or less familiar methods and paradigms e.g., quantitative and data-based research
Hold information sessions, short courses, taster sessions and facilitating a register
Co-designing with community some education videos
Facilitate mentoring and capability building
Disseminate through commercial media outlets
Development of Lived Experience frameworks and strategies
Building cross disciplinary work and new research methods – it is better when we work together
Clarifying what we mean by leadership – will leadership benefit outcomes on the ground
Finding ways to be impactful in clinical and medication research
Partnering within hospitals and services research departments

First Nations

The following section presents the key points that arose from our interview with a First Nations carer.

Key messages included:

- It is important to understand kinship, connections to family and community
- Relationships are essential. Taking the time to connect is valued
- Culturally safe environments and research methods
- Tell the community what your plans are and what you hope to get from it
- Give people time to process and feel the emotions of whether they want to participate or not
- Experiences such incarceration can further disconnect people from opportunities to participate in research

Table 5. Summary of the key points from a First Nations carer.

<table>
<tr><th colspan="2">First Nations carer (n = 1)</th></tr>
<tr><td colspan="2">Theme One: Barriers and enablers

“You don’t trust them and don’t know them so why would I want to answer their questions. With my Brothers support workers I haven’t been able to trust automatically and it has had to be built over time.” – A First Nations carer

“People not understanding our kinship and that as my younger brother’s older sister I have the same responsibility to care for him as my mother does. People also struggle to understand that no matter my brothers age, as the oldest sibling I have a responsibility to care for his needs. This is something that will carry on through our life.” – A First Nations carer</td></tr>
<tr><td>BARRIERS</td><td>ENABLERS</td></tr>
<tr><td>Not establishing rapport beforehand</td><td>Trusted by the community</td></tr>
</table>

Not having thought through appropriate questions	Meeting in a place where First Nations people feel comfortable meeting including at the persons house – this also helps build rapport
Language that makes it hard to understand what is happening (e.g. mental health language)	Knowing when to engage different members of the family, or the whole family – all a part of the recovery journey
Not taking time to explain what is going on	Being involved in research may also mean involve involving family members
Feeling like you are being engaged with just because services want something from you	The consumer feels that they have choice about who in his family is involved
Impact of incarceration	Listening to what creates safety
Not being asked about his experience while incarcerated (exclusion)	Being able to talk in person and ask questions
Being treated like the consumers mental health does not matter if they are in jail	
Theme Two: What does good effective and active involvement look like? *“There is no consultation with mob to see what we need or want. It is just assumed that people know what we need and what Is best for us.”* – A First Nations carer *“Community play a massive impact and need to be involved in the research that will impact services in the area. They need to be involved and services need to meet them where they`re at.”* – A First Nations carer	
Consistency, not using our knowledge and not following through	
The community will talk and share if they have a had a bad experience, so it is important to treat everyone equally	
Yarning feels safer instead of paperwork or online surveys. It shows the person has put interest and time into meeting	
Getting to know the local land councils and Aboriginal medial services to understand what community is going through and needs	

Using culturally safe locations
Knowing what’s happening in the community. Has there been sorry business that will keep community from attending?
Be realistic when explaining things, especially time frames. Some services may be able to deliver certain things, but it will not be within the time frame needed in a crisis.
To see where their knowledge and help has impacted the work being researched. If you offer your time and knowledge and nothing happens with it, it makes you less motivated to assist in the future. You don’t trust that people are there to really help you “I’ve heard it all before”.
Not feeling comfortable talking about cultural questions if they were not mob and had an understanding of our culture
It is also hard to relate to people if they do not have an understanding of mental health and what carers go through
The importance of sharing the results with people in community that are trusted
Take on feedback, implement into your services and then share people why this has been changed and who has helped change it. This helps people to know that the service will listen and can be trusted
Share the findings of research on a trusted social media platform, Tharawal (Aboriginal medical service) for example.
Theme Three: Research capacity building
Already building a relationship and having the carers involved from the beginning in understanding why they are involved and what they can offer
Tell the community what your plans are and what you hope to get from it. Give people time to process and feel the emotions of whether they want to do it or not.
Theme Four: Future opportunities *“In our culture people are more comfortable yarning in a group because we feed off each other and feel safe when we are together. It also helps me to know I’m not alone when I hear that other carers are going through the same thing and then I can engage and share more. Group activities are less intimidating than one on one interviews if I don’t know the person.”* A First Nations carer

The Collaborative Centre should be run in a way that is culturally safe
Allow time and breaks, traumatic experiences are hard to talk about and harder when rushed
Sharing results and building rapport with mob is key

Research and senior management allies

The following section presents the key points that arose from the ally leaders.

Key messages included:

- The right outcome measurement tools are hard to find
- The language researchers use can be hard to understand
- Workforce issues such as the casualised Lived Experience workforces makes things challenging
- Remuneration process and practices need to be developed and easy to use

Table 6. Summary of the key points from the allies focus groups.

Research and senior management allies (n= 3)	
Theme One: Barriers and enablers *"So, the first one is tokenism where you just invite people with Lived Experience to confirm your views." - Ally participant*	
BARRIERS	ENABLERS
Research is a skill set; it needs to be developed	Bringing outcome measures together to do a determination of which ones are most effective
The language used in research can be inaccessible	Opportunity for mentoring, coaching, and learning
People working in the mental health service delivery sector are busy – research takes time and inquiry	Mechanisms for paying people that are open, transparent, and clear
Casualised workforce which is not always paid at the appropriate level. Not always paid for authorship contributions	Paying Lived Experience people at an appropriate level
A lack of more substantive opportunities and continuing roles	Being mindful of providing the right team supports
Working with radically different perspectives e.g., activism	Enabling and understanding environments that are compassionate.
Category One are very highly competitive and rely on people having a strong academic research track record and a continuing university role	Listening to and then acting on Lived Experience perspectives and information
The impact of stigma and discrimination on research engagement	Being flexible and accommodating
There are concerns that people with Lived Experience will need time off, or become triggered	
Theme Two: What does good effective and active involvement look like?	

“If you genuinely think that working with people with Lived Experience is an important thing to do, then it has to run through, has to be part of everything, everything you do almost to a default.” - Ally participant
Working in non-hierarchical equitable ways
Writing people into grants as a research fellow if it is not possible to give them a permanent position as an investigator
Researchers should be mindful of the range of challenges a Lived Experience researcher will encounter
Valuing Lived Experience and commitment to this as the path forward
Theme Three: Research capacity building *“So, when the services of research Enterprise were established at the Institute of Psychiatry it was a group of people with Lived Experience doing that. And it wasn't just about them supporting other people. It was about them having a program of research that was about that was looking at things from a Lived Experience, which was important and different.”* - Ally participant
Promote Lived Experience-led research as a gold standard for the sector
Appropriately resources so that success is possible
Setting expectations that Lived Experience researchers will be involved in projects and that they will have a voice
Theme Four: Future opportunities “*But I think you know the most important thing for the collaborative centre is not getting into a tokenistic kind of thing and make sure that what they're doing is actually meaningful and that they actually track how that commitment to Lived Experience, engagement and research leads to positive outcomes and what they are so that we can actually be genuinely contributing to the evidence and to the evolution of all of this so that it comes in from the margins and becomes part of the day-to-day.”* - Ally participant
Developing new outcome measures that have strong validity and show impact/effectiveness
Develop a better sense of what research could look like in mental health organisations
Initiate Lived Experience Researcher awards in university and research award programs

Chapter Five – Synthesis and discussion

Introduction

This chapter synthesises the findings of the literature review and consultations to situate the findings from both in the broader discussion on Lived Experience leadership. This section includes carer, family and supporter perspective commentaries by Rowena Jonas and consumer feedback by Simon Katterl. These commentaries are a way of adding further richness as there was a relatively small number of carer, family, and supporter perspective publications, and few publications commenting on human rights.

Summary of overall findings from the literature review and consultations

1. **Literature promoting Lived Experience involvement in research goes back more than 20 years and has been a part of Australian mental health policy for some time. Despite this there has been little progress and Lived Experience-led research is uncommon.**
2. **More than 60% of the literature identified was from Australia suggesting that we have significant expertise in this topic. Carer/family/supporter publications were significantly under-reported.**
3. **Consumer and carer/family/supporter researchers have unique experiences and are considered separate disciplines; it is important to approach Lived Experience in a way that promotes choice and control, and which is trauma informed.**
4. **There are numerous levels of Lived Experience involvement in research from members of the community who are interested in research, research participants, Lived Experience researchers (with or without formal research qualifications) and those pursuing a formal research career.**
5. **Enablers included: establishing shared values, recognising the value and importance of including people with Lived Experience and our social movements, recognising the importance of relationships, addressing power differentials, having a critical mass and diversity of Lived Experience, using accessible language and processes, sufficient resources and remuneration, included in governance and decision-making, training and support to increase research skills.**
6. **Barriers included: lack of research skills or 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), ethics committee approval or lack of input in to application, and not included at all**

stage of the research process (e.g. research problem definition, grant application, data analysis).

7. **Lived Experience-led research is crucial. Co-production, co-design and participatory methods are essential. Areas for opportunity include increasing research capabilities across a wide range of research methods including quantitative and non-traditional methods (e.g. photobox, arts-based).**
8. **Optimal supports for people with Lived Experience who are pursuing research degrees and formal research careers it not well addressed. There is some evidence that Lived Experience research units are helpful.**
9. **Research is often experienced as ‘unfriendly’ or ‘inaccessible’. It is important to be inclusive, make sure that study materials and dissemination is accessible. Intersectionality and human rights should be well considered.**
10. **First Nations people who have a Lived Experience have said that they value creating time to create trust and recognise the importance of culturally safe practices, and the role of family and kin.**

The following sections addresses the core research questions of the project. The full set of research questions from each theme is reported in the Appendix.

What are the opportunities for the Collaborative Centre and broader mental health and wellbeing system to better promote Lived Experience leadership and engagement in mental health and wellbeing research and dissemination?

There are numerous opportunities for the Collaborative Centre and broader systems to encourage and promote people with Lived Experience in research according to the literature identified in this review. These include macro issues such as promoting Lived Experience leadership and research capabilities, while engaging in power sharing and acknowledging how the discourse is impacted by current and historical power differentials. It also means engaging with local communities to ensure that their experiences are reflected in the research and ensuring that results are shared with them. We identified other macro issues include tackling stigma – including internalised stigma and low expectations (Jakobsson, Genovesi et al. 2023) – and addressing the often harsh realities of working in the research industry (e.g., high levels of stress and pressure, ridged expectations around timelines and performance) (Hawke, Sheikhan et al. 2022, Fitzpatrick, Lamb et al. 2023). Issues around power, privilege, and the on-going social and cultural impact of experiencing distress or caring/supporting was raised in several consumer-led/consumer-oriented publications (Pinfold, Clark et al. 2015, Happell, Gordon et al. 2018, Bellingham, Kemp et al. 2021, Viksveen, Cardenas et al. 2022). As we will explore, these publications suggest the need for cultural and practice shifts within research, including acknowledgment of deficiencies in the way many researchers approach their work.

Many well-known macro influences were not identified or well addressed in the retrieved literature. In particular, the role of consumers, carers, families and supporters and the community in the development of the psychiatric pharmaceutical industry was not raised in the literature; this is a contentious area. The commercial power of the pharmaceutical industry is significant, and it has a history of disregarding the interests of consumers and their families to maintain commercial interests. None-the-less, there are so few Lived Experience researchers who have the quantitative training needed to contest evidence from drug trials, and those who work alongside drug companies are likely to be “captured”. Working alongside a pharmaceutical company could be seen by many people with Lived Experience as colluding with the “enemy”. Considering the commercial and sociocultural (e.g., biomedical) impact of this on people with Lived Experience, it was noticeably absent. This was, however, raised in the consultations by Lived Experience Leaders who said that a radical shift is needed to cast off the legacy of the medical model and create better ways of addressing mental health and wellbeing from a more constructive and effective viewpoint. 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 (Scholz, Platania-Phung et al. 2019, Scholz, Happell et al. 2021) who is an ally researcher. A small number of mixed methods studies were included (Banfield, Morse et al. 2018, Thai, Sharif et al. 2021, Li, Honey et al. 2022, Jones, Callejas et al. 2023), all of which were completed recently.

Meso-level observations include the lack of research into carer, family and supporter involvement and leadership in research. There were also obvious gaps around priority populations including First Nations, culturally and linguistically diverse, neurodiverse, people who experience disability, and LGBTIQA+ people. Issues around intersectionality were largely not addressed. A surprising finding was that there were more publications which involved young consumers in active co-researcher roles than anticipated (Blueprint Writing 2022, Viksveen, Cardenas et al. 2022, Watson, Burgess et al. 2023). Overall, many of the publications did not consider the broader social and cultural connections, including the social model of health.

The “research problem” is almost always defined by researchers and not consumers, carers, family or supporters except for some consumer and carer led publications. Like most mental health literature, the “problem” is usually defined using medical or research conceptions of mental health and wellbeing. From an insider research perspective there is often a fundamental disconnect between researchers and people with Lived Experience. Many mental health researchers have little contact with people with Lived Experience. This is compounded by micro issues such as communication, finding a common language and establishing mutual respect (Callander, Ning et al. 2011). Ideally researchers should be learning about and using language that is preferred by the people and communities we are working with.

A fundamental first step that the Collaborative Centre could take is to support people with Lived Experience to actively define the “research problems” that they would like to address, and support Lived Experience and non-Lived Experience researchers to co-produce this work in equal partnerships. There are many opportunities for the Collaborative Centre to support and lead Lived Experience development in this area. Many studies reported the value of upskilling opportunities for consumer engagement (Vescey, Yoon et al. 2022, Viksveen, Cardenas et al. 2022). There are many ways the Collaborative Centre could be involved in upskilling consumers – for example, by partnering with universities to deliver research training and link consumers in with consumer-research roles (Happell and Roper 2007, Callander, Ning et al. 2011, Hancock, Bundy et al. 2012). There is a need for Lived experience leadership at the intersection of other forms of marginalisation that may impact how consumers engage with research (Matheson and Weightman 2021, Sharmil, Kelly et al. 2021). As there is a paucity of research and leadership on intersectionality, there is an opportunity for the Collaborative Centre to support consumer and carer, family and supporter leadership on intersectionality by connecting to the local community and exploring what their research needs are. Support to develop a track record is essential to an academic career and the obtainment of grants, and an area in which Lived Experience researchers are under-supported. The support of Lived Experience research leaders to find research fellowships and PhD opportunities which support the development of this as a research trajectory with a proven track record is essential to an academic career and the obtainment of grants. The screening process for this review identified papers that were published that did not report having ethics approval (Groot, Haveman and Abma 2022, Faulkner and Thompson 2023).

Theme One: Barriers and enablers

What are the key challenges and enablers to embedding experiential knowledge within mental health and wellbeing research systems to support translational research? Lived Experience-led research is an emerging area – what are the enablers needed to support it to grow and realise this?

See below.

	Enablers	Challenges
Leadership	Strong support and belief [in Lived Experience capacity] at leadership levels	Power differentials (Happell, Gordon et al. 2018, Goldsmith, Morshead et al. 2019, Bellingham, Kemp et al. 2021, Matheson and Weightman 2021, Fitzpatrick, Lamb et al. 2023, Jakobsson, Genovesi et al. 2023, Watson, Burgess et al. 2023)
	An understanding of the consumer-survivor movement and movements behind families, carers and supporters	Perceived and actual hierarchies, status quo (Happell, Gordon et al. 2019)
	Openness to exploring and acknowledging power dynamics (Happell, Gordon et al. 2018)	Lack of research qualifications and experience (Happell and Roper 2007, Happell, Gordon et al. 2021, Viksveen, Cardenas et al. 2022)
	"Critical mass" of Lived Experience (Happell, Gordon et al. 2018)	Lived Experience researchers may be treated as service users by academic researchers (Sangill, Buus et al. 2019)
	Consider other forms of marginalisation that may impact how consumers engage with research (Matheson and Weightman 2021, Sharmil, Kelly et al. 2021)	
Social cultural	Using easy to understand language not jargon (Sangill, Buus et al. 2019) or disempowering language such as "patient researchers" (Matheson and Weightman 2021)	Stigma and low expectations (Sangill, Buus et al. 2019, Jakobsson, Genovesi et al. 2023)
	An increasing belief and acknowledgement in the value of Lived Experience and people's capacity to contribute (Viksveen, Cardenas et al. 2022)	Attitudes and preconceptions of mental health professionals (Happell and Roper 2007)
	Ensuring that non-Lived Experience researchers understand the value of consumer-survivor and family, carer and supporter research and research objectives	Not being included as an author or engaged in dissemination (Banfield, Morse et al. 2018)
	Culturally safe practices (Milroy, Kashyap et al. 2022)	

Collaboration	Activities were incremental, adaptable, responsive, and made best use of established relationships, structures, and collective leadership to meet the competing demands (Fitzpatrick, Lamb et al. 2023)	Researchers or outsiders outnumbering people with Lived Experience in numbers, power, or influence (Bond, Kenny et al. 2022)
	Shared values (Callander, Ning et al. 2011)	Tokenistic involvement (Happell and Roper 2007, Callander, Ning et al. 2011, Happell, Gordon et al. 2018, Happell, Gordon et al. 2020)
	"Critical mass" or number of Lived Experience researchers (Bond, Kenny et al. 2022)	Differing perspectives– researcher vs Lived Experience (Fitzpatrick, Lamb et al. 2023)
	Stakeholder buy-in and effective communication (Jakobsson, Genovesi et al. 2023)	Lack of on-going sustainable work (Jones, Callejas et al. 2023)
	Meaningful participation of multiple stakeholders including university relationships (Fitzpatrick, Lamb et al. 2023)	Tokenism (Happell, Gordon et al. 2018)
	Importance of peer led projects (Fitzpatrick, Lamb et al. 2023)	Lack of diversity in evaluations of engagement and evaluating engagement (Hawke, Sheikhan et al. 2023)
	Prominence and presence of people with Lived Experience (Happell, Gordon et al. 2018)	Using unrelatable language (Bellingham, Foxlewin et al. 2022, Bond, Kenny et al. 2022)
Resourcing	Opportunities to build the relationship and develop mutual trust and respect (Callander, Ning et al. 2011)	Insufficient funding (Higgs, Liao et al. 2023)
	Sufficient time and money (Callander, Ning et al. 2011, van Draanen, Jeyaratnam et al. 2013)	Pay inequality (Sangill, Buus et al. 2019, Higgs, Liao et al. 2023)
	Role of partnerships and government support (Callander, Ning et al. 2011)	Industry demands (e.g., high pressure, intense workload, competitive (Hawke, Sheikhan et al. 2022)

Research industry	Being included in governance (Blueprint Writing 2022) Lived Experience-led and informed governance	Challenges in getting Ethics approval or being left out of the Ethics process (e.g. inclusion on the Ethics Committee) (Happell, Gordon et al. 2019)
	Supportive organisational culture and institutional structures (Callander, Ning et al. 2011, Hards, Cameron et al. 2022, Higgs, Liao et al. 2023)	Many Lived Experience researchers who work with non-Lived Experience research teams experience a lack of support and understanding (Sangill, Buus et al. 2019)
	Iterative, fluid and deeply relational nature of co-created research (Fitzpatrick, Lamb et al. 2023)	Lack of dedicated LE research units (Banfield, Morse et al. 2018)
	Culture of equal and shared knowledge across all stakeholder groups (Fitzpatrick, Lamb et al. 2023)	Significant bureaucratic and HR challenges – casual status, onboarding documentation
	Training, support and tackling challenges together and with mutuality (Callander, Ning et al. 2011, Sangill, Buus et al. 2019)	Lack of evidence to support the effectiveness of co-created research (Fitzpatrick, Lamb et al. 2023)
	Support to increase the expertise and skills in research methods (Happell and Roper 2007, Hancock, Bundy et al. 2012)	Research being perceived as “higher up”, unwelcoming or alien to people who have Lived Experience so they feel less excited about participating (Boydell, Honey et al. 2021)
	Language – create shared/universal definitions (Goldsmith, Morshead et al. 2019)	Lack of clear expectations, sometimes due to researchers being unsure about how Lived Experience researchers could contribute (Sangill, Buus et al. 2019)
Research lifespan	Consistent Advisory Group meeting attendance (Banfield Randall 2018).	People with Lived Experience included selectively or not included at every stage of the research life cycle (Blueprint Writing 2022)
	Develop models and resources to guide the development of LE research across the research lifespan (2018; 2023 Hawke)	People with Lived Experience included once research project has commenced (as opposed to the conception or grant stage) (Blueprint Writing 2022)
	General and good research planning and processes (Callander, Ning et al. 2011)	Co-production of data analysis needs further development, is currently uncommon and lacking common methods (Goldsmith, Morshead et al. 2019, Fitzpatrick, Lamb et al. 2023)

These challenges and enablers should be interpreted within the limitations and biases of the literature, which predominantly reflect traditional research priorities and under-represents Lived Experience-oriented and led research. The data in this table demonstrates that people with Lived Experience often have minimal involvement in problem identification, priority setting, data analysis, dissemination and on-going (as opposed to short term) research projects. Further discussion about how to address the different, and sometimes conflicting experiences and power differentials is also important. Additional challenges identified by the consultations include only a small number of career researchers, especially carer, family, and supporter researchers. This is especially germane since most grants require investigators who have a PhD and a track record of previous grants and peer reviewed publications.

Consumer advisor perspective

Additional enablers include:

- *A strong understanding of the consumer movement by all parties involved in the collaborative research process*
- *A willingness to explore intersectional experiences of distress and of service use by non-Lived Experience researchers*
- *A commitment to human rights and the role of research in creating a more rights-compliant mental health system*
- *A commitment to share the financial and non-financial benefits of work produced, including on cultural influence and promotional opportunities on how research is shared*
- *An authorising environment set by the CEO and board for challenging research that moves away from status quo, including research that challenges power arrangements in the mental health system*

Additional barriers include:

- *The way in which incentives are set within 'the academy' around citations, certain journals and so on, and how this is misaligned to the social justice goals of many consumers and consumer researchers*

- *A lack of understanding between Lived Experience, lived expertise, and the consumer movement by non-Lived Experience practitioners*
- *A failure to understand and act to redress power imbalances to create the conditions for real interdisciplinary and collaborative research*
- *The valuing of quantitative forms of data over qualitative forms of data, with the former more commonly used and provided by consumer researchers and consumers participating in research.*

Carer, family, supporter commentary

Barriers exist for carer, family and supporter leadership in research. Lived experience researchers may be consulted some time after the research has commenced and not involved in the design, analysis or writing. This is experienced as a loss of power and control and a lost opportunity to use or develop skills to the fullest. This way the academic lexicon concerning mental health does not shift and limits possibility.

Theme Two: What does good effective and active involvement look like?

What does active and effective involvement of consumers and families, carers and supporters in research and knowledge sharing/dissemination look like?

In mental health research people with Lived Experience have traditionally been limited to playing the role of the research participant. Even now people with Lived Experience feel as though they are treated in a paternalistic way that positions them as unknowing or unskilled compared to researchers who are “benevolent teachers” or “experts”. This is reflected in many of the articles included in this review, especially those created by researchers who are endeavouring to include people with Lived Experience in their research (as required by many contemporary grants) but who do not the possess the information, skills or supports to do this in a safely and effectively.

This review identified several models that attempted to describe different levels of Lived Experience involvement including “consultation, collaboration and consumer control” (Viksveen, Cardenas et al.

2022) and “consumer advisory, consumer consultation and consumer collaboration” (Happell and Roper 2007). This challenge is illustrated in an example by (Viksveen, Cardenas et al. 2022); consultation meant that adolescent consumers perspectives were sought by researchers. Collaboration meant that closer interactive processes could occur where decisions are jointly agreed; adolescents initiated and made their own decisions but with the input and support of the researcher. From a Lived Experience perspective, this model claims to give people with Lived Experience control, but only so long as the researcher also approves. This is a significant hurdle for authentic Lived Experience research.

Lived Experience-led research is considered the highest, and preferred, level of engagement and emphasises the importance of co-production in contemporary Lived Experience discourse (Daya, Hamilton and Roper 2020). Daya, Hamilton and Roper (2020) emphasises the importance of co-production and states “as involvement of consumers/survivors in planning, delivery, and evaluation of services has increased, expectations of authentic and effective engagement, versus tokenism, have also risen”. Arnstein’s Ladder which is featured in is a useful tool for helping us reflect on the degree to which people with Lived Experience are engaged in research.

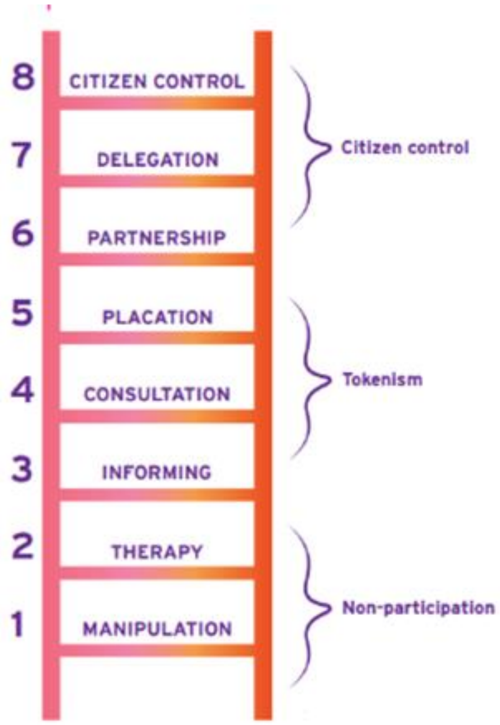


Figure 2. Arnstein's ladder (1969) - From Roper et al., "Co-production: Putting principles into practice in Mental Health Settings", 2018.

1. Non-participation (manipulation, therapy). This literature review documents that people with Lived Experience have increased their foothold in research, however, overall mental health research is still predominantly driven and produced by people who are not working from a Lived Experience point-of-view. This level also refers to research where people with Lived Experience are not consulted or are included only as participants or passive recipients of information. This level is not specifically addressed in this review and is an important area of further research. This level is impacted by systemic issues and re-enforces narratives that people with Lived Experience do not have the power to change things. A greater level of Lived Experience leadership and engagement should be aspired to.
2. Tokenism (informing, consultation, placation). With increased pressure from funders such as MRFF and NHMRC and policy, researchers are increasingly incentivised to engage people with Lived Experience and use methods such as co-production and co-design. This is starting to lead to greater awareness of Lived Experience in the research community, although there are signs in the included literature that people with Lived Experience are still often engaged on a tokenistic level, may not be appropriately remunerated and may have their contributions minimised or excluded. Although this model classifies consultation as ‘tokenism’ there is an on-going debate in contemporary practice about how feedback and good quality consultation could be done in a way that acknowledges the limitation of this method but does not see it discontinued entirely.

3. Citizen control (partnership, delegation, control). At this level people with Lived Experience should be actively leading how the research agenda are set and leading research projects (Banfield et al., 2018; Higgs et al., 2023). This literature review identified several key Lived Experience and ally authors. These authors have made significant contributions to their area of expertise, although there is a lot of territory which is yet to be addressed from a Lived Experience-led perspective. For example, this review identified that there are very few Lived Experience researchers who are producing quantitative or mixed methods research. Ideally, people with Lived Experience should be engaged and lead at every step of the research process from the development of the "research problem" thorough to data collection, analysis, synthesis and dissemination (Sangill, 2019). In Citizen Control, people with Lived Experience may be leading the research or working in equitable partnership with other key stakeholders.

The following sub sections address form of engagement that are often used but could fall on varying parts of Arnstein's Laddar depending on how they were conducted.

Co-production: Co-production is a creative process in which people with Lived Experience as consumers or carers, families and supporters are central to the planning, design, delivery and evaluation of those services which is essential to Lived Experience research and is also used in Lived Experience oriented service delivery and design. Co-production is fundamentally about sharing power and making decisions with people who use services (Jakobsson, Genovesi et al. 2023). For co-production to occur, the academic, Lived Experience researcher, and participants must be recognised as equals (Banfield, Morse et al. 2018, Blueprint Writing 2022). Co-production requires equal or more consumer researchers (Happell, Gordon et al. 2019). Co-production is about raising the standard of Lived Experience engagement; it is about moving from participation to Lived Experience leadership from the outset (Roper, Grey and Cadogan 2018). To do this there is an active partnership between people with Lived Experience and researchers through all stages of planning, defining the design, conducting, and disseminating the research (Bellingham, Foxlewin et al. 2022). Critically, researchers will share power and people with Lived Experience will be central to decision making. If this standard is not met the research should be considered research with Lived Experience engagement rather than co-production research.

An excellent example of co-production is Wellsway's fit out of the interior of Frankston's Local Mental Health and Wellbeing service. This was led by the Lived Experience Leadership Team and included a local consumer co-production team who worked with a design company. The co-production team attended workshops together, as well as a larger on-site key stake holder meeting. Workshops included interactive and visual exercises, as well as the formation of group agreements and open discussions about power and impact. Co-production included the use of two Lived Experience facilitators, power sharing and decision-making practices. The experience of this and final fit out was presented at the Victorian Mental Illness Awareness Council (VMIAC) "UnConfrence"- "How to design a Lived Experience friendly Mental Health and Wellbeing service" - in Melbourne, Australia (7-8th December).

Consumer advisor feedback

Indicators of good, effective and active involvement are:

- *Consumer (or carer, depending on the topic) researchers are the grant recipients, who can bring on non-lived experience researchers*
- *A shift in attitudes and knowledge by non-consumer researchers through the research process, such as on issues of power, medical hegemony and human rights*
- *Specialised roles for consumer researchers where position descriptions speak to the unique role of lived expertise and a knowledge of the consumer movement, as distinct from lived experience.*

Carer, family, supporter commentary

Co-produced research is just one way to move from 'expert' and 'power over' to 'partnership' and 'ownership' dynamics, the outcome which are translational and highly relevant to the people most impacted. Carer, family and supporter workers have often had education or employment interrupted and embarking on or finishing studies are often not a viable option. Authentic co-production moves the energy output of carer, family and supporter researchers from advocating for inclusion to the process to co-owning the entire project, where all members strengths are acknowledged and best utilised. Carer, family, and supporter involvement in all aspects of research will shift academic *lexicons to involve Lived Experience language and ways of knowing and doing. This creates opportunity for translation that better applies to the citizens, workforce and the mental health system and the possibility of exploring new research methods, fields and topics. There are some great examples of true co-produced and family/carer led research such as the Rising Together report.*

Lived Experience research roles: This review and consultations identified that people with Lived Experience want to have a range of ways to connect to research:

- Formal research career (with formal research experience and qualifications e.g., PhD, Masters)
- Members of the research team, research assistants and consultants (who are not required to have formal research qualifications and/or experience e.g., community voice, co-researchers, peer worker researchers)
- Research participants
- Community members who are interested in research (e.g., participating, information, connecting etc)

We noted that there was very little information in our review about what it is like to work in a university or having an academic career; this is an important topic for future research. There is currently high demand for Lived Experience researchers, especially those with PhDs to be investigators on grants. Members of the research team who are not required to have formal qualifications are an important group but, as seen in this review, can be used in a tokenistic way. Their inclusion can create original and unique perspectives but can lead to significant power differences and does not guarantee that Lived Experience input will be utilised. For example, one study by (Fitzpatrick, Lamb et al. 2023) intentionally employed two Lived Experience researchers from a non-academic background and reported that they had equal say in decisions. Several of the included studies reported increased Lived Experience engagement and leadership in research, plus the upskilling opportunities for Lived Experience people (Videmšek and Fox 2017, Goldsmith, Morshead et al. 2019, Vescey, Yoon et al. 2022, Fitzpatrick, Lamb et al. 2023). At times, researchers were often treated as “research assistants” or given more administrative or less intellectually focused jobs such as recruitment (Morse, Forbes et al. 2019, Kennedy, Gunn et al. 2023).

The research life cycle: In this review there was some evidence that people with Lived Experience were included in the development of the research method, data collection and data analysis (Sangill, Buus et al. 2019, Blueprint Writing 2022, Watson, Burgess et al. 2023). People with Lived Experience must be included at every stage of the research process, including the formative stages (McCauley, McKenna et al. 2017, Sheikhan, Kuluski et al. 2023). One study reported that young consumer co-researchers were not engaged in the development of the project aims and objectives, or stages 1 and 2 of the study (Blueprint Writing 2022), but for the most part consumer involvement was simply not reported. Sangill (2019) reported that “user-researchers” were important because of the richness that their perspective brought to the research. Watson, Burgess et al. (2023) also reported that their peer-to-peer interviews helped reduce a sense of hierarchy and opened more rich honest discussions. It was reported that we should develop and use easy to use unobtrusive tools that could be used by Lived Experience researchers/projects as part of routine service activities (entry/exit survey, evaluation wheel and), or an evaluation wheel was important; this taking in to account the participants time and potential discomfort (Fitzpatrick, Lamb et al. 2023).

The inclusion of Lived Experience researchers does not always mean that a piece of research has Citizen Control, depending on the level of power and decision making the Lived Experience researchers have, which may still be token. In the consultations people with Lived Experience highlighted that being “included” is not enough, that their inclusion must impact the research project in a meaningful way; this is a particular challenge for non-Lived Experience researchers who are not familiar with the Lived Experience movement and who do not have active connection in the community. Consumer researchers are not always treated as equal, instead they were often discussed as research assistants in need of upskilling (Scholz et al, 2019). People with Lived Experience constantly lose power and control over the end product of research, including any resulting commercial products (e.g., programs, interventions, medications). People with Lived Experience should be driving the research process including priority setting (Banfield, Morse et al. 2018).

Expert advisory groups: The use of Expert Advisory Groups and Steering Committees (2018, Bandfield; 2023 Fitzpatrick) was discussed as an important feature of contemporary mental health research. Many studies featured advisory panels (Lammers and Happell 2004, Slade, Trivedi et al. 2016, Knowles, Morley et al. 2023). This can be a token inclusion especially if the publication does not report on power-sharing and decision-making tools/processes; it is often reported by people with Lived Experience that researchers do not adopt the suggestions made by Expert Advisory groups. It was reported that planning and designing the advisory groups were important to ensuring engagement. For example, Callander, Ning et al. (2011) met monthly using hybrid technology and Boydell, Honey et al. (2021) met outside of work hours every second Saturday to increase ease of attendance. Banfield (2018) noted that letting people chose where they sit was an important gesture that signalled respect and freedom. Our publications also recommended partnership models whereby a steering committee is made up of people from all different backgrounds including Lived Experience experts (Thai, Sharif et al. (2021) so long as consumers have equal power over the conduct of the study (Pinfold, Clark et al. 2015). A well designed, inclusive, and accessible Expert Advisory Group has the potential to surpass tokenism and be a part of Citizen Control research. It should also recognise that there are diverse opinions and experiences so people's Lived Experience input (e.g., on an Expert advisory Group) is not typically generalisable or representative, many diverse points of view should be considered including those who are hard to reach (Daya, Hamilton and Roper 2020).

Consumer advisor perspective: make groups make decisions

In the consumer advisor's experience, real change comes from shifting from advisory groups to decision-making groups. The 'Not Before Time' report advised the Victorian Government on how to address harms in the mental health system. It was built on a Reference Group that decided on all of the recommendations (and advised on all aspects of the 80-page report and 9 month process). Great thought was given to getting the consent of both peak bodies, their assistance in selecting the members, the weighting of consumer/carer membership (7/3), the selection of independent consumer and carer facilitators (to address power imbalances of the project lead with others), and how we approached decision-making through a consensus-based approach. Those processes *strengthened the group, built buy-in, and produced better work. There may be considerations for how equivalent bodies in the Collaborative Centre have decision-making authority over important issues.*

Remuneration: Remuneration for Lived Experience contributors is required by the NHMRC and was reported as an essential part of Lived Experience research by publications in this review (Happell, Gordon et al. 2020, Blueprint Writing 2022, Higgs, Liao et al. 2023) and the consultations. Banfield Randall (2018) reported that "research teams should be clear from the outset about contracted hours and any funding limits which may impact on involvement at various stages." Blueprint Writing (2022) insisted on parity of pay so that their Lived Experience coresearchers were paid according to the equivalent academic pay scale. Standard remuneration rates have also been set by VMIAC, Tandem and the Victorian Department of Health.

Consumer advisor perspective: look beyond remuneration

Principles of design justice necessitate not only remuneration, but a return of wealth to the community technologies are developed for. Consider how your research will return wealth, including from any benefits that arise from your research to the communities it aims to serve.

What are new and innovative models for research and research outputs (papers, summaries etc) to be 'peer-reviewed' by people with Lived *Experience*?

Considering that there is a small number of Lived Experience researchers in Australia, especially within the carer, family, and supporter space, it is important to value their input in traditional research avenues (e.g., peer reviewed publications and conferences) as well as avenues which are more enticing to the general community. Most people cannot access peer reviewed publications, these are almost exclusively available to staff and students at universities. Consequently, incentives to publish in Open Access journals is important. Researchers are advised to speak to their University Librarian about disseminating their work due to copyright considerations; breaching copyright can lead to being blacklisted from publishers. Disseminating summaries and key learnings written in plain language is another option that was not explored in our review. Overall, little information about how to share the results with participants or the community were reported; researchers often fail to address this in the dissemination section of grant applications as well. Although Lived Experience people are increasingly asked to review grants, they usually do not get to score the grant and are often not supposed to comment on technical issues.

The sharing of research results with the community was rarely reported, although Boydell, Honey et al. (2021) identified that "a wide range of methods lay-summaries, YouTube videos and other creative means were important". The *Early Psychosis Peer Recovery Network research* model (Higgs, Liao et al. 2023) is an example of how people with Lived Experience can contribute to dissemination:

> *"This viewpoint was jointly developed in a cyclical process of writing and reflection at weekly research meetings. We worked on and discussed the draft – as well as other scholarship, activism and current events, as these were pulled into the writing process – in collaborative writing sessions. During this process, we found that our perspectives both on the article we had planned to write and on CER itself evolved, resulting in an exploration of our pathways through citizenship as researchers. In this sense, the cowriting process was not only a product of research but part of it. All four authors contributed to the writing process, led by the first author. The first three authors are research assistants with Lived Experience at a Canadian university, while the senior author is an assistant professor there."*

Higgs (2023) model of community research pathways is detailed further below.

Many dissemination strategies are not effective at reaching people in the community (e.g., people who are hospitalised, homeless, incarcerated, in long-term institutional settings, cannot access technology, live in rural or remote areas (Boydell, Honey et al. 2021). This is especially true for people for Aboriginal and Torres Strait Islanders, culturally and linguistically diverse communities as well as those with visual, hearing, or neurological/sensory diversity. Our carer, family and supporter consultations also highlighted the importance of things being easily accessible, indicating the time and resources that may be required (including emotional/psychological resources), and modes that could be easily saved and re-accessed later.

Carer, family, supporter commentary

Those who bring carer, family and supporter perspectives to academia do so on the scaffold of a range of disciplines or Lived Experience alone. There is no academic equivalent to Mad Studies to frame family/carer discourse however the carer, family and supporter practice discipline is currently being formalised. People find it difficult to access research due to the academic language barrier and journal subscriptions can be cost prohibitive. Ethics requirements are often a barrier to co-ownership as the topics can be considered too risky to the participants or researchers emotional wellbeing. What is the risk of not involving people in research which is about their own lives? Lived Experience researchers know how to manage safety, wellbeing and relationships through a research project. These are fundamental to Lived Experience practice and are skills they can and should be able to bring.

How can research be effectively translated and shared so it can be used for self-advocacy and used by consumers, families, carers, and supporters?

This question was not fully addressed by the literature identified in this review, and the participants in the consultations also found this question challenging to answer. This question may be best explored with the local community through consultations, workshops and priority setting activities. Banfield (2018) also suggested seeking feedback from the people most impacted about how to best involve them and letting them know the results of the study they were in. There was some suggestion that Lived Experience team members could help make research more accessible (Scholz et al., 2021; Banfield et al., 2018; Blueprint, 2022). Some authors suggested that regular project meetings with key stakeholders and monthly written progress reports (Banfield Randall 2018) was helpful in maintaining a communication loop in their research project; this could inform how we also engage the broader community. Some innovative and engaging dissemination methods included arts-based methods (e.g., graffiti wall) (Fitzpatrick, Lamb et al. 2023). It was also noted that qualitative research was highly valued (Fitzpatrick, Lamb et al. 2023). User-friendly formats of dissemination using 'participatory design thinking' and be easy to share (e.g. large print, plain language, languages other than English, no jargon, video, and audio) (Boydell, Honey et al. 2021).

The STELLER (Supporting the Translation into Everyday Life of Lived-Experience Research) (Boydell, Honey et al. 2021) reported their method for translating research for a Lived Experience audience:

> *STELLER conducted informal interviews with individuals impacted by mental distress in their Lived Experience network to develop an understanding of the best ways of presenting and marketing lived-experience research. The overall study (i) to translate lived-experience research findings into user-friendly attractive resources, (ii) to disseminate those resources to individuals experiencing mental illness/distress via peer workers and (iii) to evaluate their accessibility and usefulness using a non-randomised experimental study. Phase 1 included consumer consultation to explore their understanding of Lived Experience research. Phase 2 included a conference workshop explored the challenge in accessing lived-experience knowledge and refined the design aim, research questions and begin to generate ideas. Small working groups ideated about the potential ways in which lived-experience research could be shared in lay-friendly ways. This included: (i) making tangible products, (2) talking, telling and explaining and (3) acting, enacting and playing. The two-hour session was facilitated by co-author Helen Glover, consumer academic and leader. They also translated research papers into user friendly resources and used a transdisciplinary design lab (design five research team members, four design students, six individuals with lived experience, five peer workers and two members of the general public).*

Non-Lived experience researchers often did not include Lived Experience contributors as authors, or it was reported in a way that is unclear (2022 Blueprint).

Consumer advisor feedback

There are a range of considerations for ensuring that research can be used for self-advocacy:

- *Let consumers set the agenda – if consumers have set the agenda for the research, it will be more meaningful and hopeful to them, and therefore will encourage greater outcomes. Effective self-advocacy tools must start with consumers setting the agenda for the problem they want to fix (Katterl, 2019), then design the research, research dissemination or product from that (Victorian Legal Aid 2019). Research that meets a researchers' interest rather than a consumer's interests will not be easily translated into self-advocacy tools.*
- *Utilise co-production approaches for self-advocacy – utilise co-production, and to some extent user experience approaches, to design resources that help people to address the problems they define. Examples may include tools to allow people to request alternatives to predominant biomedical forms of treatment from their treating team, such as open dialogue, Hearing Voices and other methodologies that are studied by the Collaborative Centre.*
- Understand legal obligations around *accessibility – it is important that built into the foundations of the organisation is an understanding of what the right to equality under the Charter of Human Rights and Responsibilities Act 2006 (Vic), and how that will require the Collaborative Centre to put mechanisms in place to make information equally accessible to people in distress or who are neurodivergent. A policy that assigns responsibility (with capability support) will address this.*

How can the Collaborative Centre support and promote alternative strategies and ways of doing research within the mental health and wellbeing system that promotes Lived Experience research as part of interdisciplinary approaches?

This research question resonated with some literature that was identified through the review, although the "interdisciplinary" component was often implied instead of directly addressed. Mental health research often brings together traditional research and health disciplines (i.e., psychiatry, occupational therapy, social work, nursing, psychology) and increasingly recognises Lived Experience as a discipline. Consumer Lived Experience and Carer, Family and Supporter Lived Experience are recognised as unique and separate disciplines. Interdisciplinary collaborative projects in Victoria include combined workshops and training for clinicians on confidentiality; collaborative work with clinicians to improve the use of mental health outcome measures; more joint presentations at conferences, such as the Australian and New Zealand Mental Health Services Conference; and the work of the consumer and carer subcommittee of the Victorian Ministerial Advisory Committee (Callander, Ning et al. 2011).

Our review and consultations identified that consumers and carers, family and supporters usually work separately, and often feel safer working this way. Opportunities to learn from both consumer and carer, family, supporter perspectives are important to addressing many research problems (Banfield 2018, Banfield Randall 2018); this is an emerging area of development and should be done in consultation with those involved. Safe and effective interdisciplinary research should address systemic issues, be transparent about research objectives and values, undertake a thoughtful planning process, involve researchers with Lived Experience from the beginning and continually challenge the stigma experienced by Lived Experience researchers (Hawke, Sheikhan et al. 2022). Lived Experience research could do this through methods which increase reflection and accountability (e.g., project meetings, Lived Experience action logs etc). It is important to identify safe and constructive ways of working across disciplines, including Lived Experience disciplines that have distinct and sometimes conflicting needs; this was noted in the consumer and carers, families, and supporters Lived Experience Leaders interviews.

It was noted that peer workers already have many skills, attitudes, and the experience to do many research tasks and that this increased their vocational skills (Honey, Boydell et al. 2022). Banfield Randall (2018) suggested strategies such as: i) work with community organisations; ii) conduct skill-building workshops; iii) focus on specific tasks; iv) recruit and engage participants in ways that work best for them v) build research. Other strategies included advertising research opportunities in a way that promotes access across different parts of the community (Blueprint Writing 2022), the development of training resources for consumer researchers (e.g., for data collection and grant applications) (Hancock, Bundy et al. 2012, Bellingham, Foxlewin et al. 2022) debriefs (Callander, Ning et al. 2011, Blueprint Writing 2022). Blueprint Writing (2022) 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 et al. 2012). Reflective and development opportunities such as creating an active dialoguing between the research and co-researchers and time for consumer researchers to reflect about their role, as individuals and as consumer leaders was important (Videmšek and Fox 2017), as was mentoring - learning how to do interviews over time (Blueprint Writing 2022).

Lived Experience research and co-research has an “emancipatory” potential and should be explored as a mechanism for interdisciplinary understanding, transformation, and equality (Fitzpatrick, Lamb et al. 2023). Research that includes a critical appraisal of bias and the impact of the biomedical system (e.g. diagnosis, medication etc) are necessary. Research that explores or establishes other conceptions and representations which are derived from people’s Lived Experience may capture information which lead to new solutions that could not be captured by traditional methods (Daya, Hamilton and Roper 2020). Increased access to Lived Experience research, which is often difficult to find and access, may improve health practitioners understanding of Lived Experience (Boydell, Honey et al. 2021) and this was highlighted. This could be especially effective in service-based research.

Consumer advisor perspective

Ways to do things differently can include:

- *Collectively ask foundational questions like ‘what is this system for?’ and ‘which workers or parties benefit most and least from the current arrangements?’ and develop a critical and shared understanding of what the purpose of a system is, and what it should be*
- *Allowing consumers to set the outcomes they want to achieve, such as the elimination of seclusion and restraint within the service, and then develop the research questions, team, methodologies and frameworks to achieve that aim*
- *Start with Yes Survey, complaints and data, and work back – identify the areas of the service that are most welcomed and most complained about by consumers, and develop research to maximise the best and address the problems*
- *Commit to eliminating coercion – if research is to be truly different, it needs to move away from complicity or silence on coercion, meaning that all research should aid the elimination of, or at the very least provide no support for, coercion*

Carer, family, supporter commentary

Lived Experience Leadership was identified in the Royal Commission into Mental Health in Victoria as fundamental to reform. A series of grants were available for Lived Experience workforce to build leadership capability through undergraduate and postgraduate studies in a range of study areas. Family/carer workers who "fall" into research feel they are less skilled or educated or feel that what they bring is lesser than theoretical knowledge. They often need to advocate for genuine involvement and then experience 'imposter syndrome' when the technical aspects of research become a barrier.

Non-academic carer, family and supporter peer researchers rely on academic researchers, within a research team, for their expertise in research design methods, the ethics approval process, how to publish and more. Carer, family and supporter peer practice professionals understand Lived experience practice elements but not necessarily research skills. Carer, family and supporter peer practice professionals who are not trained academic researchers often report they feel their professional and personal expertise is 'less than' that of other professionals. Many peers say this due primarily to the questioning of peer discipline legitimacy, ie Lived Experience knowledge not being part of dominate forms of discourse (academic research) or acceptable forms of knowledge (Western biomedical models).

Academic researchers of the Carer, Family and Supporter Discipline in the future will not necessarily have Lived Experience of caring, so research teams will continue to rely on co-constructed research to ensure Lived Experience expertise remains central, improving quality and translation.

What examples exist of promising practice or models the Collaborative Centre can draw on?

This section presents a summary of some key models that were identified through the literature search.

Viksveen's collaborative relationship model (Viksveen, Cardenas et al. 2022)

Collaborating at every stage of research:

1. Commitment motivated by altruism, personal interests, and a common purpose.
2. Inclusiveness and support to reduce social uncertainty and strengthen collaboration.

3. Reduced power differentials while ensuring clarity of roles and tasks.
4. Diversity in representation to expand the perspectives of ‘the adolescent voice’.
5. Self-determination- supporting adolescents' involvement in decision-making processes.
6. Flexible and systematic project management.

Lived Experience co-production (Roper, Grey and Cadogan 2018)

This piece of grey literature is often considered the seminal co-production model for Australian mental health service development and research. The figure below provides a succinct representation of how co-planning, codesign, co-evaluation and co-delivery intersect to create co-production. It explores the role of power, who should be involved and real-life examples.

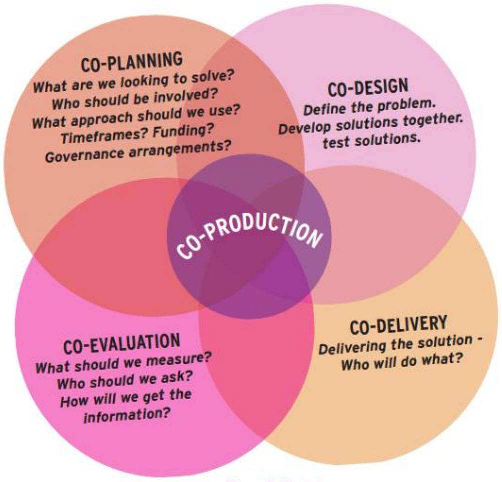


Figure 1. What does co-production involve?

Figure 3. What does co-production involve?

Lived Experience-led collaborative research units

ACACIA: The ACT Consumer and Carer Mental Health Research Unit (Banfield Randall 2018)

Led by Michelle Banfield at the National Centre for Epidemiology and Population Heath, College of Health and Medicine at the Australian National University ACACIA works with ACT consumers and carers, families, and supporters to conduct research on the issues that are most important to the local community. Banfield provided a great example of the benefit of establishing a Lived Experience research unit (ACACIA) (Banfield 2018 and Banfield Randall 2018). This meant that they were able to access and capability build as a unit so that they were able to use Lived Experience researchers in a range of roles including facilitators (Banfield 2018). ACACIA has five primary objectives which speak to the entire research lifecycle: i) consumer and carer involvement in setting the research agenda; ii) consumer and carer involvement in developing effective involvement methods; iii) research training and capacity-building for consumer and carer-led research; iv) Lived Experience research dissemination; and v) using the results of the first four objectives to influence ACT policy and practice (Banfield Randall 2018).

Figure 4. ACACIA model of Lived Experience-led mental health research

Working with diverse perspectives in mental health research, policy, and practice

A model for authentic consumer engagement (Daya, Hamilton and Roper 2020)

This model draws on consumer/survivor materials and explicitly addresses diverse experiences of treatment and care, that have contributed to a rich consumer/survivor advocacy agenda. Daya, Hamilton and Roper (2020) propose a strong co-production model that is made possible by recognizing and welcoming consumer/survivor activist, facilitator, transformer, and humaniser contributions that could inform future research. This article could further inform research through the graphic tools it includes and its exploration on language.

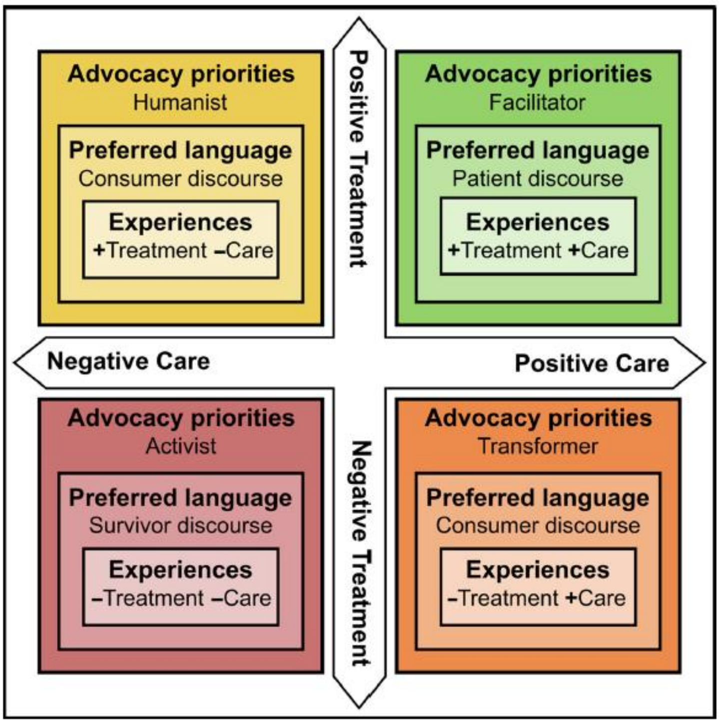
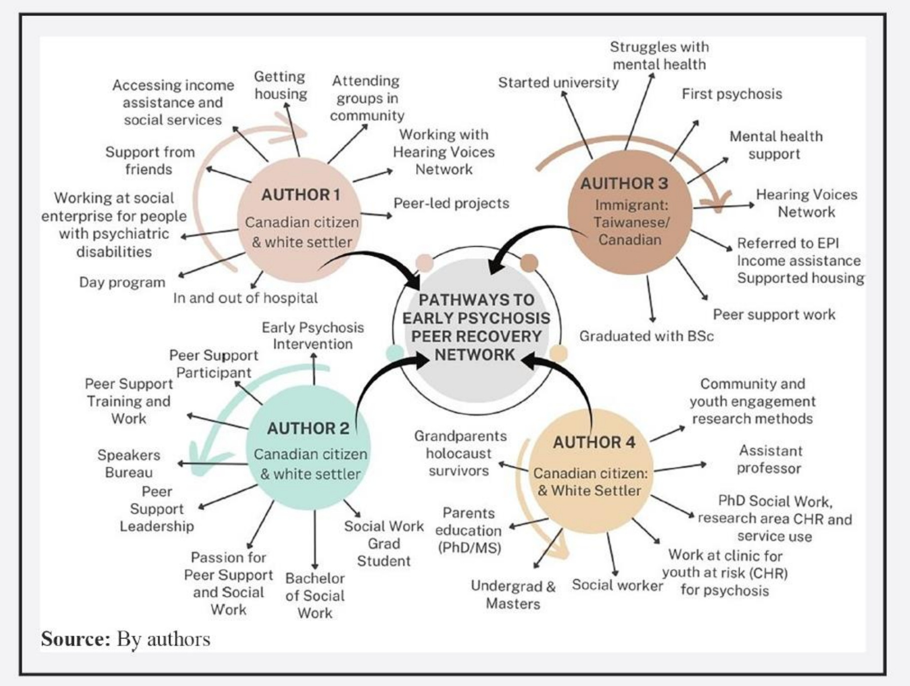


Figure 5. Integrated model: Experiences, preferred language, and advocacy priorities.

A model of community pathways to enable and drive research (Higgs, Liao et al. 2023)

A community-based and engaged model of an early psychosis peer recovery network

This model is also discussed above and provides an interesting model of social engagement as demonstrated through four social contexts.



Source: By authors

Figure 6. Higg's model of community pathways to research

Lived Experience within research institutes

Integrating Lived Experience within research institutions (Hawke, Sheikhan et al. 2022)

Hawke's paper defines a Lived Experience academic or research as someone who has formal research qualifications (e.g., doctoral or advanced degree) who is working in a research role, and this model should be interpreted accordingly. It was one of the few papers to approach Lived Experience from a university perspective. Future work exploring and defining what it is to be a "Lived Experience researcher" is important to the development and implementation of Lived Experience research.

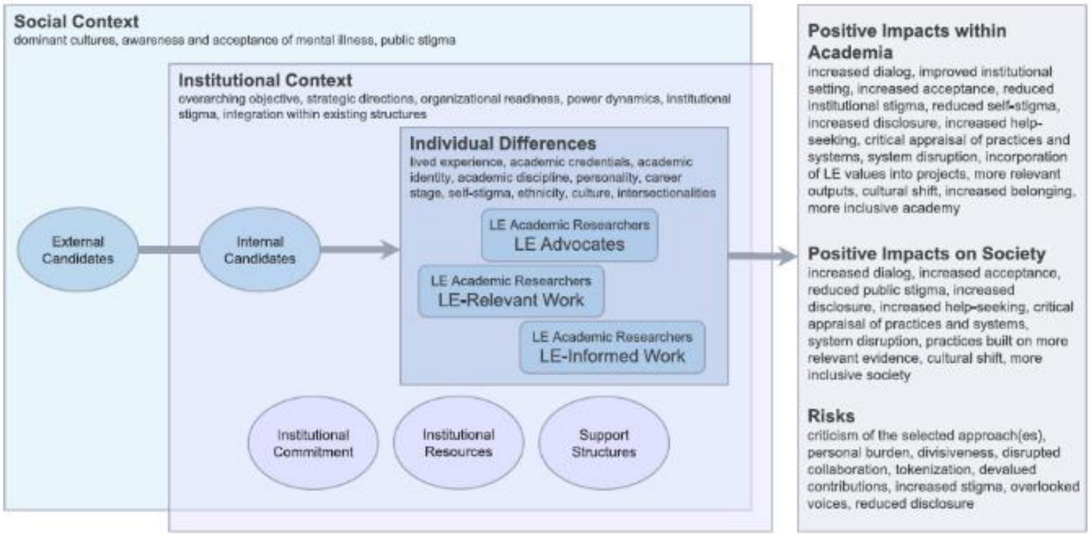


Figure 7. Factors affecting the embedding of academic researchers with Lived Experience within a research institution

Theme Three: Research capacity building

How can the Collaborative Centre build capacity to better promote Lived Experience leadership and engagement in research across the mental health and wellbeing system?

Capability building can lead to cultural and system level change by increasing people's empathy, mutual commitment, and stronger connections with Lived Experience (Fitzpatrick, Lamb et al. 2023), it also encourages us to look at who is being excluded (Hards et al., 2022). Overall, the participants in the consultations found this theme the most challenging to answer; it was more strongly addressed in the review but should be explored by tapping into our local Lived Experience, research, and mental health service communities. It is essential to increase the capacity of Lived Experience researchers and to increase the capacity for Lived Experience-led research. Although there is some Lived Experience-led research in this review, it is by a relatively small number of authors.

Some publications reported capability building processes for Lived Experience researchers. For example, the LERT training model (Bellingham, Foxlewin et al. 2022) was comprised of 10 two-hour research training workshops, that were co-delivered by Lived Experience and non-Lived Experience researchers. Each workshop covered designated topics (e.g., introduction to research design and practice; levels of Lived Experience contribution in research; qualitative, quantitative, and arts-based methodologies and was presented by Lived Experience researchers. Blueprint Writing (2022) delivered online training modules that included an introduction to the study; the role of co-researcher and guidance on using Lived Experience; qualitative research; research integrity and ethics; skills practice. The training was adapted from a research methods training handbook developed for public and patient involvement (PPI) and was delivered by members of the research team. Of note, this study did not utilise coresearchers until part way through the study and they were not included in the design of the objectives (Blueprint Writing 2022).

Consumer advisor perspective

Additional strategies could include:

- *Enhance the visibility and power of Lived Experience – ensure that Lived Experience structures such as the Lived Experience Advisory Panel have visibility and the capacity to make their own statements and determine their own work agendas. Enable robust mechanisms of accountability, such as reporting responsibilities on research and other matters of interest to LEAP, to demonstrate the serious role it has in leadership of the organisation.*
- *Create seeding programs – enable the LEAP or other Lived Experience researchers to seed work in other parts of the system, which are reported to LEAP and shared by LEAP in partnership with those Lived Experience researchers.*
- *Enhance social capital – use the tools and capabilities of the Collaborative Centre – including its news, reach, communications capacities, coordinating opportunities and more – to elevate the work of other Lived Experience researchers in the state.*

How can emerging Lived Experience researchers and consumers and families, carers, and supporters with an interest in research be supported to develop their skills and experience? What does good practice look like?

This question was not richly addressed in the review or the consultations. Consumers and carers, family and supporters and the community should be provided with a range of options regarding developing research skills and opportunities. People with Lived Experience should be consulted about whether they would prefer to receive support and opportunities which combine consumer and carer, family, and supporter attendees or whether it should be in separate groups. Our engagement methods for the consultations found that consumers and carers, family and supporters had a range of preferences and appreciated being able to choose which felt right for them. Consumers and carer, family, supporters have a strong history of collective leadership (Fitzpatrick, Lamb et al. 2023) which could be pivotal.

Further research, preferably from a Lived Experience point of view, should explore the career pathways of Lived Experience researchers. Increasing the number of Lived Experience researchers could increase opportunity and provide mentoring and supervision for Lived Experience higher degree students. "Grant funding" was the first suggestion from our carer focus group. Increased grant funding could enable Lived Experience academics to increase Lived Experience representation in research. Research skills are often learned through mentoring and learning on the job. The review identified projects that used Lived Experience researchers during recruitment, analysis (Goldsmith, Morshead et al. 2019, Blueprint Writing 2022) and dissemination (Griffiths, Jorm and Christensen 2004, Callander, Ning et al. 2011). Mentoring and training were significant themes in our consultations. Participating in research can also be a gateway to Lived Experience research and can be rewarding for both Lived Experience researchers (Happell and Roper 2009, Hawke, Sheikhan et al. 2022) and participants (Boydell, Honey et al. 2021).

What would opportunities for career progression look like for Lived Experience researchers?

There was a dearth of information addressing this research question; further research on this using more specific inquiry is required. Profiles, interviews and pathway mapping with existing Lived Experience researchers could inform future developments. Initial indications from the review highlighted the importance of Lived Experience research units (Banfield, 2018), the importance of having Lived Experience authors including Lived Experience authors who partner with allies or work in an interdisciplinary way . The role of training and mentoring was also emphasised in the consultations. In addition to traditional research careers, it is important to consider the range of research pathways that could exist for the Lived Experience community. Sangill (2019) stated that “user-researchers’ experiences influenced their analysis of data, and some user-researchers were reported to contribute to qualitative data analysis by expanding the horizon of data analysis, adding insight, depth and complexity to the analysis.” This may be an avenue for bringing new Lived Experience people into research activities including a formal research pathway. Peer workers could participate in research and dissemination, especially research that is centred around mental health services and supports (Honey, Boydell et al. 2022). This question may best be explored by further interviews with current Lived Experience researchers and allies that support Lived Experience researchers, noting that this is a rapidly shifting space which is strongly influenced by local factors such as one’s state and particular university. Future, pathways may include positioning Lived Experience researchers in leadership positions within universities such as La Trobe University’s Lived Experience Strategic Lead role and as research and development leads within service delivery organisations.

Consumer advisor perspective

Opportunities for career progression could include starting with the outcome and then building the roles to meet that – determine the outcomes that the Collaborative Centre wants to achieve both through research translation and service delivery, ensuring those outcomes are co-developed with lived expertise, and then co-develop the roles that will assist the Collaborative Centre to get there

Conclusion

This concludes the synthesis of the review and consultation findings. This chapter highlights that there is still much to learn about how people with Lived Experience would like to be involved in and supported to lead, create and disseminate research. Many parts of research are not addressed in the findings that we have so far. Deciding how we move forward together will be an interesting journey, some considerations are offered in the final Chapter.

Chapter Six – Recommendations and conclusions

This Chapter includes some suggestions about how these recommendations can inform the completion of the Collaborative Centre's "Translational Research Strategy". As well as a summary of key recommendations, the full recommendations are also detailed below.

This project is a part of the development of the Collaborative Centre's "Translational Research Strategy" which explores how people with Lived Experience, researchers and those in service delivery and design can work together to translate research into better outcomes and happier lives.

Introduction

This project is a part of the development of the Collaborative Centre's "Translational Research Strategy" which explores how people with Lived Experience, researchers and those in service delivery and design can work together to translate research into better outcomes and happier lives; these recommendations take this translational context in to account. This section brings together the findings of the project and presents our recommendations about how the Collaborative Centre could promote people with Lived Experience to lead, create and disseminate research.

This Chapter will also address the final two research questions:

- How can the Collaborative Centre, through its Translational Research Strategy and broader functions, support these opportunities as part of its approach to interdisciplinary translational research, dissemination, and capacity building?
- How do we measure the impact and outcomes achieved through better promotion of Lived Experience leadership and engagement in mental health and wellbeing research and dissemination?

Recommendation One: Organisations are underpinned by the principle ‘Nothing about us, without us’ – Leading with Lived Experience

Primary goal: Create a research culture that is Lived Experience-centred and led. Where people with Lived Experience feel like the research being conducted reflects their experiences, priorities and could improve things that are important to them. The broader community should also have increased opportunities to access and explore mental health research.

Top 5 recommended actions:

1. Develop a quality improvement tool to audit Lived Experience research and knowledge translation culture. Organisations must lead by example by creating a strong Lived Experience culture that embeds people with Lived Experience throughout the organisation including in leadership positions. This should include Lived Experience supervision.

2. Create engagement opportunities that honour the diverse and sometimes conflicting experiences of consumers and carers (i.e. in research design - be intentional in creating safe places for both consumers and carers through separate and joint codesign sessions). Organisations must recognise the unique, distinct but sometimes conflicting experiences that consumers and carers, family and supporters can have. Creating engagement opportunities which honour this, are trauma-informed and gives people choice and control.

3. Create an online portal that shares accessible and easy-to-understand information using a range of mediums (e.g. art, video, interactive activities). Include First Nations driven and produced material. Organisations must establish a community presence. Participate in community and organisational events in person.

4. Create a ‘Lived Experience Research Review Board’. The Board’s role will be to define and uphold the standard for Lived Experience research, co-production and co-design, Lived Experience engagement and dissemination. This Board could provide approval (similar to an ethics committee)

and accreditation, as well as support education and training. It could also provide support and advice to existing Human Research Ethics Committees to improve their Lived Experience capabilities.

5. Develop, implement and evaluate the tools (e.g. checklist for meetings and projects that documents the role of people with Lived Experience, power sharing tools, etc), frameworks (e.g. a Lived Experience Knowledge Translation Framework) and guidelines (e.g. Lived Experience wellbeing and trauma informed practice guidelines) to support the integration of Lived Experience values and practices. This should have a consumer-lead and a carer and family and supporter lead, as well as a diverse working group. We recommend working with First Nations organisations and communities.

Recommendation Two: Organisations create opportunities for people with Lived Experience, researchers and mental health services to work together to create effective knowledge translation

Primary goal – To bring together people from Lived Experience, research, peer work and mental health services to work together to create impactful knowledge translation. At the moment these stakeholder groups are often not well connected. By working together, we could improve the outcomes of consumers, carers, family and supporters through knowledge translation.

Top 5 recommended actions:

1. Create a Lived Experience Strategic Lead role who could develop relationships with people who have Lived Experience, consortium partners, peak bodies, universities, research institutes, peer workers, mental health services, the community and other key stakeholders.

2. Create a ‘Lived Experience Research and Knowledge Translation Development Unit’ to support pipelines for development. This could support the development of formal research pathways for people with Lived Experience by working with universities to develop Lived Experience dedicated subjects, research training, mentoring, early career and mid-career support, support and training for PhD/Masters supervisors and general Lived Experience research capability-building activities. It should administer Conference Bursaries for people with Lived Experience, especially non-researchers and grant support. It should support the development and implementation of Lived Experience Expert Decision-making Groups and Expert Advisory Groups. It should include a specific focus on

carer, family and supporter researchers as well as peer workers involved in research and grant applications, as these are under-represented groups that have great potential.

3. Create a dedicated 'Lived Experience-led Knowledge Translation Network' that brings together people with Lived Experience, Lived Experience researchers, mental health researchers, peer workers, service providers and other key stakeholders to work together to improve outcomes for consumers, carers, families and supporters. This network should contain a members register, and work in partnership with the Lived Experience peak bodies, including their participation registers. This should meet quarterly (hybrid) and be overseen by a Lived Experience-led (consumer and carer, family and supporters) advisory group, plus working groups.

4. Develop and support a 'Allyship and Supporter Program'. Currently mental health research is predominately conducted by people who are not working from a Lived Experience discipline lens. An Allyship program could improve their Lived Experience capabilities. It could also support mental health professionals who have Lived Experience and are seeking to develop discipline specific knowledge, skills and capabilities. This should be Lived Experience-led and co-produced with consumers, carers, family and supporters.

5. Create a research and knowledge translation "Connectors Program" to support partnership across Lived Experience, research, peer work and mental health services. Develop Lived Experience-led flexible, accessible and hybrid networking and skill sharing events to support partnership across Lived Experience, research and mental health services. Develop and implements a secondment program to promote pathways from peer work to knowledge translation; this could include a dedicated consumer-only and carer, family and supporter-only branch. It could contain a mentoring program.

Recommendation Three: Create opportunities for people with Lived Experience to be contributors and leaders at every stage of the research life cycle

Primary goal – To create dynamic, meaningful, and informative ways to lead, create and disseminate research. Build a community of people who are Lived Experience-oriented (including peer workers) who would like to engage with research. This should be aimed at the whole community, including carers, family and supporters, and should be accessible, culturally safe and in languages important to the community.

Top 5 recommended actions:

1. Create opportunities for people with Lived Experience (including peer workers) to decide what should be researched and set research priorities. Create a series of interactive workshops and priority setting activities. This should be informed by existing priority setting projects and be reviewed regularly. This could also be done online through the organisation's websites in an on-going way through a feedback portal.

2. Conduct person and online community engagement activities. Informative and fun events could engage people who would not normally connect to conventional research (e.g. Lived Experience Ted talk event, TikTok? "Vibe me up - Stories of hope" competition, partnerships with Lived Experience-led arts and theatre companies, YouTube videos, Auslan mad poetry slam etc). Partners could include the Victorian Department of Health's 'Social Prescribing' unit, consortium partners and Lived Experience-led and First Nations organisations.

3. Organisation should create a dedicated 'Lived Experience Leadership Program' which focuses specifically on leadership capabilities for those working in knowledge translation including peer workers. This program should be Lived Experience-led and run. It could provide people a chance to present their work, problemsolve leadership topics and form partnerships. Consumers and carers, family and supporters should be given flexible participation options, and may prefer to meet separately.

4. Develop and implementation of inclusive and accessible translational research practices. Members of the community who are from culturally and linguistically diverse background, people who experience disability, identify as LGBTIQA+, have experienced incarceration or are often left out of knowledge translation. There needs to be specific projects that explore barriers to participation and potential solutions (e.g. meeting in the community, developing community relationships, meeting face-to-face, etc).

5. Co-produce Lived Experience measurement tools and methods to measure the effectiveness of services and supports, as well as participant experience.

Recommendation Four: Bring together people with Lived Experience and key stakeholders to improve the outcomes that matter most to consumers, carers, family and supporters.

Primary goal: To establish ways of working together that are safe, respectful and constructive.

Top 5 recommended actions:

1. Develop Lived Experience-led wellbeing practices to support knowledge translation activities. This should be led by a consumer and a carer, family and supporters lead, and informed by a Lived Experience advisory or decision-making group. This should develop tools, resources and knowledge that will support safe participation and trauma informed ways to work together. It should include a dedicated First Nations focus; this should be First Nations-led.

2. Create a statement of 'Lived Experience Commitment' to outline how organisations will work with people who have Lived Experience on all projects and at all levels of the organisation. This could be Lived Experience-led, and roles should be co-developed with people who have Lived Experience. Routine data should be collected about organisations' fidelity to this.

3. Conduct a mentoring and support program for peer workers to develop and run Lived Experience research projects within their service.

4. Conduct networking and educational programs which increase connection between Lived Experience, research and service delivery and development. Opportunities to increase mutual understanding, present and share ideas and create partnerships is key to knowledge translation.

5. Create a Lived Experience dissemination program. This could include the collection of Lived Experience papers and conference slides. It should also store or make accessible peer reviewed and grey literature and archival audio-visual material from the local Lived Experience community (e.g. My Consumer Place). A network for sharing work should be established, and a "3MT: 3-minute thesis" or short plain language video summary collection could be formed.

Recommendation Five: Action to support First Nations people and communities

Primary goal – To put First Nations people and communities at the heart of social and emotional wellbeing

Top 5 recommended actions:

1. Create pathways and initiatives that support First Nations people to drive translational research. First Nations people and communities are often left out of research. This review found very few publications that talked about First Nations people leading, creating or disseminating research. This is a critical absence. More targeted reviews and consultations should be conducted to map this important area.

2. Create dedicated First Nations Research and Knowledge Translation Leads who could co-ordinate First Nations teams and play a pivotal role in cementing organisation's culture around reconciliation and cultural safety. Their role could include building consumer, carer, family, supporter and kinship relationships, including relationships with First Nations organisations. These Leads could also lead the First Nations contributions and support the development of ethics applications and processes. They should have capacity to mentor and support other First Nations people working in the translational space.

3. Develop relationships with First Nations organisations and communities to create a 'First Nations Action Plan' that is culturally safe. Invest in time and relationships and get to know each person's relationship and preferences about including mob and kin. The language should be culturally specific and talk to First Nations themes such as looking at someone's spirit, not just their mental and physical health. Take time to understand the bigger picture.

4. Develop and share information, resources and training to increase First Nations specific capabilities and culturally safe capabilities in non-First Nations people working in research and knowledge translation. This should be done by working with First Nations people and communities.

5. A 'First Nations Statement of Commitment' should be developed; this should be First Nations-led and conducted. Organisations should set firm targets and commitments about First Nations social

and emotional wellbeing and fidelity to this should be evaluated every 12 to 18 months. Results and updates should be reported in the Annual report.

Recommendation Six: Evaluate the impact of organisations who support Lived Experience leadership and involvement in research and dissemination

Primary goal - Assess the impact of organisations who promote Lived Experience leadership, creation and dissemination of research, and the outcomes important to this

Top 5 recommended actions:

1. Conduct formal Lived Experience-led evaluations of the knowledge translation process. Co-design the outcomes of interest, aims, participants/key stakeholders, data collection techniques, data analysis and dissemination. This could include organisations' Quality and Safety data, organisational data and routinely collected feedback. The evaluation of innovations and projects should also be conducted. An external Lived Experience evaluator should be engaged when required.

2. Evaluate the impact of the organisations support for Lived Experience knowledge translation on key stakeholders including internal staff, consortium and government partners, industry impact, event and activity participants, people with Lived Experience and the community. Impact and experience could be explored through a network/relationship analysis, surveys, interviews and consultations. Arts-based and creative methods should be explored. Key indicators could include Alt Metrics (LinkedIn, Twitter, etc), publication and conference attendance, increase in Lived Experience PhD enrolments/completions), increased Lived Experience engagement, governance and leadership, and community recognition.

3. Collect and evaluate organisational data that identifies the number of Lived Experience people involved in organisations. Include analysis of the organisational chart, number of leadership positions and other contributors. Plus, other feedback, complaints and information. Develop and implement a brief Lived Experience-led feedback and evaluation tool to measure the experience of Lived Experience participants in meetings, groups and other activities; this should be included in service data and analysed as part of a larger evaluation.

4. Evaluate targets relating to First Nations people's engagement and leadership in the organisation against the organisations commitments and policies, as well as First Nations advice. It should also review First Nations participants experience and feedback. This should be collected and then shared with First Nations leaders and the community in a way that works for them and is culturally safe.

5. Disseminate the findings of the evaluation through a special report, in the Annual Report and other accessible platforms (e.g. YouTube video, organisations webpage, etc).

Limitations and future directions

Overall, we noted that the search strategy used identified a wide range of publications about the topic but was unlikely to pick up studies that did not use the same search terms in the title or abstract. Survivor research, Lived Experience leadership regarding carers, family and supporters, were not addressed as strongly as expected and warrant investigation using more targeted methods; this may be a result of the methods which took a broad sweep of the literature. Similarly, we noted that there were less articles about participatory action research and co-production in research than we were expecting. The research pathways of PhDs and early career Lived Experience researchers was not well documented.

We strongly recommend a review of research by Lived Experience researchers to explore what can be learned from these practice examples which may not have met the inclusion criteria for this review. Likewise future exploration of peer worker roles in translational research will likely lead to important new information. This review did not directly address the experience of being a participant in a mental health study or broader publications that may have been completed by someone with Lived Experience but did not meet the reviews inclusion criteria.

Conclusion

This concludes this research report. We have established the state of the literature and explored this topic through consultations. The Collaborative Centre can play a pivotal role in improving the real-world outcomes of consumers and carers, family, and supporters by centralising Lived Experience in mental health research. The Collaborative Centre should support people with Lived Experience, research skills and mental health organisations to find new ways to define and solve challenges together.

References

ABS. (2007). *National survey of mental health and wellbeing: Summary of results*. ABS.

Ainsworth, S., Alvarez-Vasquez, S., Edan, V., Johnson, B., Randall, R., Roper, C., Sellick, K., Smale, K., & Switserloot, J. (2020). *Leading the change: Co-producing safe, inclusive workplaces for consumer mental health workers*. Melbourne Social Equity Institute.

Alegría, M., NeMoyer, A., Falgàs Bagué, I., Wang, Y., & Alvarez, K. (2018). Social determinants of mental health: Where we are and where we need to go. *Curr Psychiatry Rep*, *20*(11), 95.

Anthony, W. A. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosoc Rehabi J*, *16*(4), 11-23.

Armstrong, V., & LeFrancois, B. (2021). *Interrogating mad studies in the Academy*. Routledge.

Ash, C., & Otiende, S. (2023). *Meaningful engagement of people with Lived Experience: A framework and assessment for measuring and increasing Lived Experience leadership across the speectrum of engagment*. National Survivor Network - CAST

Sophie Otiende, Global Fund to End Modern Slavery. Accessed from: https://nationalsurvivornetwork.org/wp-content/uploads/2023/01/2023-Meaningful-Engagement-of-People-With-Lived-Experience-Toolkit.pdf

Australian Commission on Safety in Healthcare. (2023). *Partnering with consumers standard.* Accessed from: https://www.safetyandquality.gov.au/standards/nsqhs-standards/partnering-consumers-standard

Australian Government - Department of Health. (2017). *The Fifth National Mental Health and Suicide Prevention Plan*. Accessed from: http://www.coaghealthcouncil.gov.au/Portals/0/Fifth%20National%20Mental%20Health%20and%20Suicide%20Prevention%20Plan.pdf

Banfield, M., Morse, A., Gulliver, A., & Griffiths, K. (2018). Mental health research priorities in Australia: A consumer and carer agenda. *Health Res Policy Syst*, *16*(1), 119-119.

Banfield, M., Randall, R., O'Brien, M., Hope, S., Gulliver, A., Forbes, O., Morse, A. R., & Griffiths, K. (2018). Lived experience researchers partnering with consumers and carers to improve mental health research: Reflections from an Australian initiative. *Int J MH Nurs*, *27*(4), 1219-1229.

Banfield, M. A., Morse, A. R., Gulliver, A., & Griffiths, K. M. (2018). Mental health research priorities in Australia: A consumer and carer agenda. *Health Res Policy Syst*, *16*(1), 119.

Bellingham, B., Foxlewin, B., Rose, G., & River, J. (2022). *CMHDARN - Co-production Kickstarter.* Accesssed from https://cmhdaresearchnetwork.com.au/resource/co-production-kickstarter/

Bellingham, B., Kemp, H., Boydell, K., Isobel, S., Gill, K., & River, J. (2021). Towards epistemic justice doing: Examining the experiences and shifts in knowledge of lived experience researchers over the course of a mental health research training programme. *Int J MH Nurs*, *30*(6), 1588-1598.

Beresford, P., & Russo, J. (2021). *The Routledge international handbook of mad studies*. Routledge.

Blueprint. (2022). A Blueprint for involvement: Reflections of Lived Experience co-researchers and academic researchers on working collaboratively. *Res Involv Engagem*, *8*(1), 68.

Bond, J., Kenny, A., Mesaric, A., Wilson, N., Pinfold, V., Kabir, T., Freeman, D., Waite, F., Larkin, M., & Robotham, D. J. (2022). A life more ordinary: A peer research method qualitative study of the Feeling Safe Programme for persecutory delusions. *Psychol Psychother*, *95*(4), 1108-1125.

Boydell, K. M., Honey, A., Glover, H., Gill, K., Tooth, B., Coniglio, F., Hines, M., Dunn, L., & Scanlan, J. N. (2021). Making Lived-Experience research accessible: A design thinking approach to co-creating knowledge translation resources based on evidence. *Int J Enviro Res Public Health, 18*(17), 02.

Callander, R., Ning, L., Crowley, A., Childs, B., Brisbane, P., & Salter, T. (2011). Consumers and carers as partners in mental health research: Reflections on the experience of two project teams in Victoria, Australia. *Int J Ment Health Nurs*, *20*(4), 263-273.

Case, A. D., Byrd, R., Claggett, E., DeVeaux, S., Perkins, R., Huang, C., Sernyak, M. J., Steiner, J. L., Cole, R., LaPaglia, D. M., Bailey, M., Buchanan, C., Johnson, A., & Kaufman, J. S. (2014). Stakeholders' perspectives on community-based participatory research to enhance mental health services. *Am J Community Psychol*, *54*(3-4), 397-408.

Centre for Mental Health Learning. (2019a). *Carer perspective supervision: A framework for supporting the mental health family/carer lived experience workforce*. Accessed from: https://cmhl.org.au/sites/default/files/resources-pdfs/CPSF_final_digital_compressed%20%28optimized%29.pdf

Centre for Mental Health Learning. (2019b). *Strategy for the family carer mental health workforce in Victoria*. Accessed from: https://cmhl.org.au/sites/default/files/resources-pdfs/Family-Carer-Strategy-web-2A.pdf

Commonwealth of Australia. (2021). *Prevention, compassion, care: National Mental Health and Suicide Prevention Plan*. Accessed from: https://www.health.gov.au/sites/default/files/documents/2021/05/the-australian-government-s-national-mental-health-and-suicide-prevention-plan-national-mental-health-and-suicide-prevention-plan.pdf

Daya, I. (2022). Russian dolls and epistemic crypts: A lived experience reflection on epistemic injustice and psychiatric confinement. *Incarceration*, *3*(2), 26326663221103445.

Daya, I., Hamilton, B., & Roper, C. (2020). Authentic engagement: A conceptual model for welcoming diverse and challenging consumer and survivor views in mental health research, policy, and practice. *Int J MH Nurs*, *29*(2), 299-311.

Deloitte's. (2021). *The value of informal care in 2020*. Accessed from: https://www.deloitte.com/au/en/services/economics/perspectives/value-of-informal-care-2020.html

Edan, V., Sellick, K., Ainsworth, S., Alvarez-Varquez, S., Johnson, B., Smale, K., Randall, R., & Roper, C. (2021). Employed but not included: The case of consumer-workers in mental health care services. *Int J Hum Resour Manag*, *32*(15), 3272-3301.

Epstein, M. (2013). *History of the consumer movement. Our Consumer Place*. Accesssed from: https://www.ourcommunity.com.au/files/OCP/HistoryOfConsumerMovement.pdf

Faulkner, A., Carr, S., Gould, D., Khisa, C., Hafford-Letchfield, T., Cohen, R., Megele, C., & Holley, J. (2021). 'Dignity and respect': An example of service user leadership and co-production in mental health research. *Health Expect*, *24*(S1), 10-19.

Faulkner, A., & Thompson, R. (2023). Uncovering the emotional labour of involvement and co-production in mental health research. *Disabi Soc*, *38*(4), 537-560.

Fitzpatrick, S. J., Lamb, H., Stewart, E., Gulliver, A., Morse, A. R., Giugni, M., & Banfield, M. (2023). Co-ideation and co-design in co-creation research: Reflections from the 'Co-Creating Safe Spaces' project. *Health Expect*, *26*(4), 1738-1745.

Fox, J. (2020). Experiences of user involvement in mental health research: Exploring reflections from a service user researcher using auto-ethnography. *Ment Health Review*, *25*(3), 281-294.

Goldsmith, L. P., Morshead, R., McWilliam, C., Forbes, G., Ussher, M., Simpson, A., Lucock, M., & Gillard, S. (2019). Co-producing randomized controlled trials: How do we work together? *Front Sociol*, *4*, 21.

Griffiths, K. M., Jorm, A. F., & Christensen, H. (2004). Academic consumer researchers: A bridge between consumers and researchers. *Aust NZ J Psychiatry*, *38*(4), 191-196.

Groot, B., Haveman, A., & Abma, T. (2022). Relational, ethically sound co-production in mental health care research: Epistemic injustice and the need for an ethics of care. *Crit Public Health*, *32*(2), 230-240.

Hancock, N., Bundy, A., Tamsett, S., & McMahon, M. (2012). Participation of mental health consumers in research: Training addressed and reliability assessed. *Aust Occup Ther J*, *59*(3), 218-224.

Happell, B., Donovan, A. O., Warner, T., Sharrock, J., & Gordon, S. (2022). Creating or taking opportunity: Strategies for implementing expert by experience positions in mental health academia. *J Psychiatr Ment Health Nurs*, *29*(4), 592-602.

Happell, B., Ewart, S. B., Platania-Phung, C., & Stanton, R. (2016). Participative mental health consumer research for improving physical health care: An integrative review. *Int J Ment Health Nurs*, *25*(5), 399-408.

Happell, B., Gordon, S., Bocking, J., Ellis, P., Roper, C., Liggins, J., Platania-Phung, C., & Scholz, B. (2018). How did I not see that? Perspectives of nonconsumer mental health researchers on the benefits of collaborative research with consumers. *Int J Ment Health Nurs*, *27*(4), 1230-1239.

Happell, B., Gordon, S., Bocking, J., Ellis, P., Roper, C., Liggins, J., Scholz, B., & Platania-Phung, C. (2018). Turning the tables: Power relations between consumer researchers and other mental health researchers. *Issues Ment Health Nurs*, *39*(8), 633-640.

Happell, B., Gordon, S., Bocking, J., Ellis, P., Roper, C., Liggins, J., Scholz, B., & Platania-Phung, C. (2019). "Chipping away": Non-consumer researcher perspectives on barriers to collaborating with consumers in mental health research. *J Ment Health*, *28*(1), 49-55.

Happell, B., Gordon, S., Roper, C., Ellis, P., Waks, S., Warner, T., Scholz, B., & Platania-Phung, C. (2021). Establishing an expert mental health consumer research group: Perspectives of nonconsumer researchers. *Perspect Psychiatr Care*, *57*(1), 33-42.

Happell, B., Gordon, S., Roper, C., Scholz, B., Ellis, P., Waks, S., Warner, T., & Platania-Phung, C. (2020). 'It is always worth the extra effort': Organizational structures and barriers to collaboration with consumers in mental health research: Perspectives of non-consumer researcher allies. *Int J Ment Health Nurs*, *29*(6), 1168-1180.

Happell, B., Gordon, S., Sharrock, J., Donovan, A. O., Kenny, N., & Warner, T. (2023). There is something about oppression: Allies' perspectives on challenges in relationships with experts by experience. *Int J Ment Health Nurs*, *32*(3), 744-754.

Happell, B., & Roper, C. (2007). Consumer participation in mental health research: Articulating a model to guide practice. *Australas Psychiatry*, *15*(3), 237-241.

Happell, B., & Roper, C. (2009). Promoting genuine consumer participation in mental health education: A consumer academic role. *Nurse Educ Today*, *29*(6), 575-579.

Happell, B., Scholz, B., Gordon, S., Bocking, J., Ellis, P., Roper, C., Liggins, J., & Platania-Phung, C. (2018). "I don't think we've quite got there yet": The experience of allyship for mental health consumer researchers. *J Psychiat Ment Health Nurs*, *25*(8), 453.

Hards, A., Cameron, A., Sullivan, E., & Kornelsen, J. (2022). Actualizing community-academic partnerships in research: A case study on rural perinatal peer support. *Res Involv Engagem*, *8*(1), 73-73.

Hards, A., Cameron, A., Sullivan, E., & Kornelsen, J. (2022). Actualizing community-academic partnerships in research: A case study on rural perinatal peer support. *Res Involv Engagem*, *8*(1), 73.

Hawke, L. D., Sheikhan, N. Y., Jones, N., Slade, M., Soklaridis, S., Wells, S., & Castle, D. (2022). Embedding lived experience into mental health academic research organizations: Critical reflections. *Health Expect*, *25*(5), 2299-2305.

Hawke, L. D., Sheikhan, N. Y., Roberts, S., & McKee, S. (2023). Research evidence and implementation gaps in the engagement of people with Lived Experience in mental health and substance use research: A scoping review. *Res Involv Engagem*, *9*(1), 32.

Higgs, R., Liao, A., Windsor, T., & Ben-David, S. (2023). Meeting in the middle: Experiences of citizenship in community-engaged psychosis research. *J Public Ment Health*, *22*(1), 12-24.

Honey, A., Boydell, K., Clissold, N., Coniglio, F., Do, T. T., Dunn, L., Fuller, C. J., Gill, K., Glover, H., Hines, M., Scanlan, J. N., Tooth, B., & Wagner, D. (2022). Peer workers disseminating lived experience research: A perfect match? *J Ment Health Train Educ Pract*, *17*(5), 408-418.

Howard, P., & el-Mallakh, P. (2001). Training consumers to collect data in mental health service system evaluation research. *J Psychosoc Nurs Ment Health Serv*, *39*(5), 30-39.

Jakobsson, C. E., Genovesi, E., Afolayan, A., Bella-Awusah, T., Omobowale, O., Buyanga, M., Kakuma, R., & Ryan, G. K. (2023). Co-producing research on psychosis: A scoping review on barriers, facilitators and outcomes. *Int J Ment Health Syst*, *17*(1), 25.

Jones, N., Atterbury, K., Byrne, L., Carras, M., Brown, M., & Phalen, P. (2021). Lived Experience, research leadership, and the transformation of mental health services: Building a researcher pipeline. *Psychiatr Serv, 72*(5), 591-593.

Jones, N., Callejas, L., Brown, M., Colder Carras, M., Croft, B., Pagdon, S., Sheehan, L., Oluwoye, O., & Zisman-Ilani, Y. (2023). Barriers to meaningful participatory mental health services research and priority next steps: Findings from a national survey. *Psychiatr Serv*, *74*(9), 902-910.

Katterl, S., Lambert, C., MacBean, C., Grey, F., Downes, L., Cataldo, M. L., Clarke, K., & Williams, S. (2023). Not Before Time: Lived Experience-led justice and repair (Advice to the Victorian Minister for Mental Health, February 2023). Accessed from: www.livedexperiencejustice.au

Kennedy, A. J., Gunn, K. M., Duke, S., Jones, M., Brown, E., Barnes, K., Macdonald, J., Brumby, S., Versace, V. L., & Gray, R. (2023). Co-designing a peer-led model of delivering behavioural activation for people living with depression or low mood in Australian farming communities. *Aust J Rural Health*, *31*(3), 556-568.

King, C., & Gillard, S. (2019). Bringing together coproduction and community participatory research approaches: Using first person reflective narrative to explore coproduction and community involvement in mental health research. *Health Expect*, *22*(4), 701.

Knowles, S., Morley, K., Foster, R., Middleton, A., Pinar, S., Rose, F., Williams, E., Hendon, J., & Churchill, R. (2023). Collaborative evaluation of a pilot involvement opportunity: Cochrane Common Mental Disorders Voice of Experience College. *Health Expect*, *26(6),* 2428-2440*.*

Knowles, S., Sharma, V., Fortune, S., Wadman, R., Churchill, R., & Hetrick, S. (2022). Adapting a codesign process with young people to prioritize outcomes for a systematic review of interventions to prevent self-harm and suicide. *Health Expect*, *25*(4), 1393-1404.

Kruzan, K. P., Meyerhoff, J., Biernesser, C., Goldstein, T., Reddy, M., & Mohr, D. C. (2021). Centering Lived Experience in developing digital interventions for suicide and self-injurious behaviors: User-centered design approach. *JMIR Ment Health*, *8*(12), e31367.

Lambert, N., & Carr, S. (2018). 'Outside the original remit': Co-production in UK mental health research, lessons from the field. *Int J MH Nurs*, *27*(4), 1273-1281.

Lammers, J., & Happell, B. (2004). Research involving mental health consumers and carers: A reference group approach. *Int J Ment Health Nurs*, *13*(4), 262-266.

Lee, G. Y., McKenna, S., Song, Y. J. C., Hutcheon, A., Hockey, S. J., Laidler, R., Occhipinti, J. A., Perry, C., Lindsay-Smith, T., Ramsay, A., Choi, S., Feirer, D., Shim, A. W., Cottle, J., Mukherjee, A., New, J., Yu, R., Scott, E. M., Freebairn, L., & Hickie, I. B. (2023). Strengthening mental health research outcomes through genuine partnerships with young people with lived or living experience: A pilot evaluation study. *Health Expect*, *26*(4), 1703-1715.

Li, S., Honey, A., Coniglio, F., & Schaecken, P. (2022). Mental health peer worker perspectives on resources developed from lived experience research findings: A Delphi study. *Int J Environ Res Public Health*, *19*(7), 3881.

Matheson, C., & Weightman, E. (2021). Research and recovery: Can patient participation in research promote recovery for people with complex post-traumatic stress disorder, CPTSD? *Health Expect*, *24 Suppl 1*(Suppl 1), 62-69.

Maylea, C. (2022). Mad hats - A reflection on mad leadership. *Int Mad Studies J*, *1*(1), e1-9.

McCauley, C., McKenna, H., Keeney, S., & McLaughlin, D. (2017). Service user engagement: A co-created interview schedule exploring mental health recovery in young adults. *J Adv Nurs*, *73*(10), 2361-2372.

Milroy, H., Kashyap, S., Collova, J., Mitchell, M., Derry, K. L., Alexi, J., Chang, E. P., & Dudgeon, P. (2022). Co-designing research with Aboriginal and Torres Strait Islander consumers of mental health services, mental health workers, elders and cultural healers. *Aust J Rural Health*, *30*(6), 772-781.

Mitchell Institute. (2022). *Being Equally Well implementation action plan for better health care and longer lives for people living with serious mental illness*. Victoria University, Mitchell Institute.

Morse, A. R., Forbes, O., Jones, B. A., Gulliver, A., & Banfield, M. (2019). Australian mental health consumer and carer perspectives on ethics in adult mental health research. *J Empir Res Hum Res Ethics*, *14*(3), 234-242.

National Eating Disorders Collaboration. (2019). *Developing a peer workfroce for eating disorders: Exploring the evidence*. NEDC.

National Health and Medical Research Council. (2018). *Keeping research on track: A companion document to ethical conduct in research with Aboriginal and Torres Straights Islander People and communities*. NHMRC.

National Mental Health Consumer and Carer Forum. (2021). *NMHCCF perspective on Lived Experience and mental health research*. NMHRC.

NSW Ministry of Health – Experience Team. (2023). *All of us: An introduction to our guide to engaging consumers, carers and communities across NSW Health*. NSW Government.

Our Future Project Partnership. (2021). *Our future: Developing introductory training for the Lived and Living Experience workforces in Victoria.* Self Help Addiction Resource Centre.

Paino, E., River, J., Bellingham, B., Brien, B., Cruickshank, S., D'Lima, R., Grace, R., Heffernan, T., Henkel, D., Isobel, S., Kemp, H., Stott, S., Thorburn, K., Gusheh, M., & Zappalà, G. (2023). *Towards a meaningful evaluation framework for peer work: Short report 2023.* University of Technology Sydney, Centre for Social Justice and Inclusion.

Pinfold, V., Clark, M., Szymczynska, P., Hamilton, S., Peacocke, R., Dean, S., Clewett, N., Manthorpe, J., & Larsen, J. (2015). Co-production in mental health research: Reflections from the People Study. *Ment Health Rev J*, *20*(4), 220-231.

Productivity Commission. (2019). *Mental Health: Productivity Commission draft report (volume 1 to 3)*. Commonwealth of Australia.

Productivity Commission. (2020). *Mental Health, Inquiry Report.* Accessed from: https://www.pc.gov.au/inquiries/completed/mental-health#report

Ramon, S., Healy, B., & Renouf, N. (2007). Recovery from mental illness as an emergent concept and practice in Australia and the UK. *Int J Soc Psychiatry*, *53*(2), 108-122.

Rising Together Action Group. (2022). *Rising together - Lifting the lid on the experiences of family/carer lived experience workers*. University of Melbourne.

Roberts, G., & Boardman, J. (2013). Understanding 'recovery'. *Advances in Psychiatric Treatment*, *19*(6), 400-409.

Roper, C., Grey, F., & Cadogan, E. (2018). *Co-production: Putting principles into practice in mental health contexts*. University of Melbourne.

Rose, D. (2017). Service user/survivor-led research in mental health: Epistemological possibilities. . *Disabil Soc*, *32*(6), 773-789.

Rose, D., Carr, S., & Beresford, P. (2018). 'Widening cross-disciplinary research for mental health': What is missing from the Research Councils UK mental health agenda? *Disabil Soc*, *33*(3), 476-481.

Royal Commission into Victoria's Mental Health System. (2020). *2020 Witness statements*. Victorian Governement. Accessed from: http://rcvmhs.archive.royalcommission.vic.gov.au/2020-witness-statements.html

Royal Commission into Victoria's Mental Health System. (2021). *Royal Commission into Victoria's Mental Health System, Final Report, Volume 1-5: Transforming the system—innovation and implementation, Parl Paper No. 202, Session 2018–21 (document 6 of 6)*. Accessed from: https://finalreport.rcvmhs.vic.gov.au/download-report/

Sangill, C., Buus, N., Hybholt, L., & Berring, L. (2019). Service user's actual involvement in mental health research practices: A scoping review. *Int J MH Nurs*, *28*(4), 798-815.

Sangill, C., Buus, N., Hybholt, L., & Berring, L. L. (2019). Service user's actual involvement in mental health research practices: A scoping review. *Int J MH Nurs 28*(4), 798-815.

Schirmer, J., Mylek, M., & Miranti, R. (2022). *Caring for others and yourself: 2022 Carer wellbeing survey – Full data report*. Carers Australia and the University of Canberra.

Scholz, B., Gordon, S., Bocking, J., Liggins, J., Ellis, P., Roper, C., Platania-Phung, C., & Happell, B. (2019). 'There's just no flexibility': How space and time impact mental health consumer research. *Int J MH Nurs*, *28*(4), 899-908.

Scholz, B., Happell, B., Gordon, S., Warner, T., Roper, C., Ellis, P., Waks, S., & Platania-Phung, C. (2021). 'People just need to try it to be converted!': A picture of consumer mental health research in Australia and New Zealand. *Issues Ment Health Nurs*, *42*(3), 249-255.

Scholz, B., Platania-Phung, C., Gordon, S., Ellis, P., Roper, C., Bocking, J., & Happell, B. (2019). Very useful, but do carefully: Mental health researcher views on establishing a Mental Health Expert Consumer Researcher Group. *J Psychiatr Ment Health Nurs*, *26*(9-10), 358-367.

Sharmil, H., Kelly, J., Bowden, M., Galletly, C., Cairney, I., Wilson, C., Hahn, L., Liu, D., Elliot, P., Else, J., Warrior, T., Wanganeen, T., Taylor, R., Wanganeen, F., Madrid, J., Warner, L., Brown, M., & de Crespigny, C. (2021). Participatory Action Research-Dadirri-Ganma, using Yarning: Methodology co-design with Aboriginal community members. *Int J Equity Health*, *20*(1), 160.

Sheikhan, N. Y., Kuluski, K., McKee, S., Hiebert, M., & Hawke, L. D. (2023). Exploring the impact of engagement in mental health and substance use research: A scoping review and thematic analysis. *Health Expect*, *26*(5), 1806-1819.

Sinclair, A., Gillieatt, S., Fernandes, C., & Mahboub, L. (2023). Inclusion as assimilation, integration, or co-optation? A post-structural analysis of inclusion as produced through mental health research on peer support. *Qual Health Res*, *33*(6), 543-555.

Slade, M., Trivedi, P., Chandler, R., & Leamy, M. (2016). Developing involvement during a programme of recovery research. *J Ment Health Train Educ Pract*, *11*(4), 244-255.

State Government of Victoria. (1986). *Victorian Mental Health Act*. State Government of Victoria.

State Government of Victoria. (2014). *2014 Victorian Mental Health Act.* State Government of Victoria. Accessed from: https://www.health.vic.gov.au/practice-and-service-quality/mental-health-act-2014

Thai, H., Sharif, N., Patrick, K., Meldrum, C., Gamble, T., Robertson, C., Wright, N., Fogl, T., Webb, A., Tutino, J., Bahl, N., O'Brien, B., & Team. (2021). A Participatory Action Research (PAR) exploratory initiative for psychosis recovery and resilience. *Psychosis*, *13*(2), 143-153.

van Draanen, J., Jeyaratnam, J., O'Campo, P., Hwang, S., Harriott, D., Koo, M., & Stergiopoulos, V. (2013). Meaningful inclusion of consumers in research and service delivery. *Psychiatr Rehabil J*, *36*(3), 180-186.

Vescey, L., Yoon, J., Rice, K., Group, Members of PARCO Group, Davidson, L., & Desai, M. (2022). A return to lived experiencers themselves: Participatory action research of and by psychosocial clubhouse members. *Front Psychol*, *13*, 962137.

Victorian Government. (2023). *Diverse Communities Mental Health and Wellbeing Framework and Blueprint*. Accessed from: https://www.health.vic.gov.au/mental-health-wellbeing-reform/diverse-communities-mental-health-and-wellbeing-framework-and-blueprint

Victorian Legal Aid. (2019). *New resources help consumers speak up and protect their rights*. Accessed from: https://www.imha.vic.gov.au/about-us/news/new-resources-help-consumers-speak-up-and-protect-their-rights

Videmšek, P., & Fox, J. (2017). Exploring the value of involving experts-by-experience in social work research: Experiences from Slovenia and the UK. *Eur J Soc Work*, *21*(4), 498-508.

Viksveen, P., Cardenas, N. E., Ibenfeldt, M., Meldahl, L. G., Krijger, L., Game, J. R., Andvik, M. M., Cuddeford, O., Duerto, S., Mustafa, M., & Tong, M. (2022). Involvement of adolescent representatives and coresearchers in mental health research: Experiences from a research project. *Health Expect*, *25*(1), 322-332.

VMIAC. (2023a). *Brief guide to Lived Experience engagement in research*. Accessed from: https://www.vmiac.org.au/research-intro/lived-experience-research-toolkit/

VMIAC. (2023b). *Doing trauma-informed research with people with Lived Experience*. VMIAC.

VMIAC. (2023c). *Lived Experience principles checklist*. VMIAC. Accesssed from: https://www.vmiac.org.au/research-intro/lived-experience-research-toolkit/

VMIAC. (2023d). *Research participant checklist*. VMIAC Council. Accesssed from: https://www.vmiac.org.au/research-intro/lived-experience-research-toolkit/

VMIAC. (2023e). *VMIAC research strategy*. VMIAC.

Watson, R., Burgess, L., Sellars, E., Crooks, J., McGowan, R., Diffey, J., Naughton, G., Carrington, R., Lovelock, C., Temple, R., Creswell, C., & McMellon, C. (2023). A qualitative study exploring the benefits of involving young people in mental health research. *Health Expect*, *26*(4), 1491-1504.

Webb, M., Cooper, C., Hemming, L., Dalton, A., Unity, E., Simmons, M., Bendall, S., & Robinson, J. (2023). *Guidelines for involving young people with lived and living experience of suicide in suicide research*. Orygen.

Wellways Australia. (2023). *Wellways supports 'Not before Time' report on systems harms.* Accessed from: https://www.wellways.org/wellways-news/news/wellways-supports-not-before-time-report-on-systems-harms

Wyder, M., Barratt, J., Jonas, R., & Bland, R. (2021). Relational recovery for mental health carers and family: Relationships, complexity and possibilities. Br J Soc Work, 52(3), 1325–1340.

World Health Organisation. (2023). *WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions*. WHO. Accessed from: https://www.who.int/groups/gcm/meaningful-engagement-of-people-with-lived-experience

Worsley, J., McKeown, M., Wilson, T., & Corcoran, R. (2022). A qualitative evaluation of coproduction of research: 'If you do it properly, you will get turbulence'. *Health Expect*, *25*(5), 2034-2042.

Appendixes

Appendix 1. Full list of database search words

A. Stream 1: Mental Health	Stream 2: Consumer Involvement	Stream 3: Leadership
Mental Health	Lived experience	Workforce
Mental distress	Lived and living experience	Leader*
Emotional distress	Life experience	Engagement
Psychological distress	Lived experience-led	Expertise
Psychiatric distress	Lived and living-led	Consumer
Mental illness	Expert by experience	Involvement
Mental ill-health	Peer*	Lived experience
Mental ill health	Consumer	Co-production
Mental disorders		Coproduction
Psychiatric survivor*		Codesign
Service user*		Co-design
Psychiatric crisis		Collaboration
In-patient*		Participation
Inpatient*		Partnership
Eating disorder*		Consultation
Psychosis		Citizen control

Personality disorder* Emotional trauma Psychological trauma Suicidal ideation Suicide attempt Self-harm Carer Caregive* Informal support Kinship group Support person Family		Solution Dissemination Knowledge Translation Self-advoca* Information sharing Employ*

Appendix 2. The original research questions – in full

Barriers and enablers

A. What are the key challenges and enablers to embedding experiential knowledge within mental health and wellbeing research systems to support translational research?

B. Lived experience-led research is an emerging area – what are the enablers needed to support it to grow and realise impact?

What does good effective and active involvement look like?

A. What does active and effective involvement of consumers and families, carers and supporters in research and knowledge sharing/dissemination look like? For example:

B. What are new and innovative models for research and research outputs (papers, summaries etc) to be 'peer-reviewed' by people with lived experience?

C. How can research be effectively translated and shared so it can be used for self-advocacy and use by consumers, families, carers, and supporters?

D. How can the Collaborative Centre support and promote alternative strategies and ways of doing research within the mental health and wellbeing system that promotes lived experience research as part of interdisciplinary approaches?

E. What examples exist of promising practice or models the Collaborative Centre can draw on?

Research capacity building

A. How can the Collaborative Centre build capacity to better promote lived experience leadership and engagement in research across the mental health and wellbeing system?

B. How can emerging lived experience researchers and consumers and families, carers, and supporters with an interest in research be supported to develop their skills and experience? What does good practice look like?

C. What would opportunities for career progression look like for lived experience researchers?

Future opportunities

B. How can the Victorian Collaborative Centre, through its Research Strategy and broader functions, support these opportunities as part of its approach to interdisciplinary translational research, dissemination, and capacity building?
C. How do we measure the impact and outcomes achieved through better promotion of lived experience leadership and engagement in mental health and wellbeing research and dissemination?

Appendix 3. Included peer reviewed publications

Authors	Title	Journal	Country	Design	Focus	Lived Experience roles (if identified)
Banfield et al. (2018)	Mental health research priorities in Australia: A consumer and carer agenda	Health Res Policy Syst	Australia	Mixed methods	Consumers and carers, families, and supporters	Authors, investigators, participants
Banfield, Randall et al. (2018)	Lived Experience researchers partnering with consumers and carers to improve mental health research: Reflections from an Australian initiative	Int J Ment Health Nurs	Australia			
Bellingham, Kemp et al. (2021)	Towards epistemic justice doing: Examining the experiences and shifts in knowledge of Lived Experience researchers over the course of a mental health research training programme	Int J Ment Health Nurs	Australia	Qualitative	Consumers	Authors
Blueprint Writing (2022)	A Blueprint for Involvement: Reflections of Lived Experience co-researchers and academic researchers on working collaboratively	Res Involv Engagem	UK	Research report	Young consumers	Researchers, unclear if authors

Authors	Title	Journal	Country	Design	Focus	Lived Experience roles (if identified)
Bond, Kenny et al. (2022)	A life more ordinary: A peer research method qualitative study of the Feeling Safe Programme for persecutory delusions	Psychol Psychother	UK	Qualitative study of an intervention study	Consumers who experience psychosis	Patient Advisory Group (n = 4 study participants)
Boydell, Honey et al. (2021)	Making lived-experience research accessible: A design thinking approach to co-creating knowledge translation resources based on evidence	Int J Env Res Pub He	Australia	Research report	Consumers	Authors, researchers
Callander, Ning et al. (2011)	Consumers and carers as partners in mental health research: Reflections on the experience of two project teams in Victoria, Australia	Int J Ment Health Nurs	Australia	Research report	Consumers and carers, families, and supporters	Authors, consumer project team, consumer Peak Body partners
Case, Byrd et al. (2014)	Stakeholders' perspectives on community-based participatory research to enhance mental health services	Am J Community Psychol	US	Research report	Consumers	Unclear
Daya et al. (2020)	Authentic engagement: A conceptual model for welcoming diverse and challenging consumer and	Int J Ment Health Nurs	Australia	Narrative	Consumers	Consumer-led, authors, researchers

Authors	Title	Journal	Country	Design	Focus	Lived Experience roles (if identified)
	survivor views in mental health research, policy, and practice					
Faulkner, Carr et al. (2021)	‘Dignity and respect’: An example of service user leadership and co-production in mental health research	Health Expect	UK	Qualitative	Consumers	Consumer-led, consumer researchers
Fitzpatrick, Lamb et al. (2023)	Co-ideation and co-design in co-creation research: Reflections from the 'Co-Creating Safe Spaces' project	Health Expect	Australia	Research report	Consumers with thoughts of suicide	Authors, independent consumer and carer representatives, staff, and consumer representatives from Territory consumer and carer peaks, and representatives from ACT Health
Fox (2020)	Experiences of use involvement in mental health research: Exploring reflections from a service user researcher using auto-ethnography	Ment Health Rev	UK	Auto-ethnography	Consumers	Authors, consumer researchers

Authors	Title	Journal	Country	Design	Focus	Lived Experience roles (if identified)
Goldsmith, Morshead et al. (2019)	Co-producing Randomized Controlled Trials: How do we work together?	Front Social	UK	Research report - reflection on an RCT	Consumers	Research team (trial manager), two managers of a peer support service, peer worker (working in the NHS) and two experienced service user researchers and 9 consumer research assistants
Griffiths et al. (2004)	Academic consumer researchers: A bridge between consumers and researchers	Aust NZ J Psychiatry	Australia	Research report	Consumers	Unclear
Groot et al. (2020)	Relational, ethically sound co-production in mental health care research: Epistemic injustice and the need for an ethics of care	Crit Public Health	Netherlands	Research report	Consumers	Unclear - no ethics approval
Hancock et al. (2012)	Participation of mental health consumers in research: Training addressed, and reliability assessed	Aust Occup Ther J	Australia	Research report	Consumers	Authors, consumer trainee researchers

Authors	Title	Journal	Country	Design	Focus	Lived Experience roles (if identified)
Happell, Donovan et al. (2022)	Creating or taking opportunity: Strategies for implementing expert by experience positions in mental health academia	J Psychiatr Ment Health Nurs	Australia	Research report	Consumers	Authors
Happell et al. (2016)	Participative mental health consumer research for improving physical health care: An integrative review	Int J Ment Health Nurs	Australia	Review	Consumers - physical health	Unclear
Happell et al. (2018)	How did I not see that? Perspectives of non-consumer mental health researchers on the benefits of collaborative research with consumers	Int J Ment Health Nurs	Australia	Qualitative	Consumers	Authors
Happell et al. (2018)	Turning the tables: Power relations between consumer researchers and other mental health researchers	Int J Ment Health Nurs	Australia	Qualitative	Consumers	Authors
Happell, Gordon et al. (2019)	"Chipping away": Non-consumer researcher perspectives on barriers to collaborating with consumers in mental health research	J Ment Health	Australia	Qualitative	Consumers	Authors

Authors	Title	Journal	Country	Design	Focus	Lived Experience roles (if identified)
Happell, Gordon et al. (2021)	Establishing an expert mental health consumer research group: Perspectives of non-consumer researchers	Perspect Psychiatr Care	Australia	Qualitative	Consumers	Authors
Happell, Gordon et al. (2020)	'It is always worth the extra effort': Organizational structures and barriers to collaboration with consumers in mental health research: Perspectives of non-consumer researcher allies	Int J Ment Health Nurs	Australia	Qualitative survey	Consumers	Authors
Happell, Gordon et al. (2023)	There is something about oppression: Allies perspectives on challenges in relationships with experts by experience	Int J Ment Health Nurs	Australia	Qualitative	Consumers	Authors
Happell et al. (2007)	Consumer participation in mental health research: Articulating a model to guide practice	Australas Psychiatry	Australia	Qualitative review	Consumers and carers, families, and supporters	Authors

Authors	Title	Journal	Country	Design	Focus	Lived Experience roles (if identified)
Happell and Roper (2009)	Promoting genuine consumer participation in mental health education: A consumer academic role	Nurse Educ Today	Australia	Research report	Consumers	Authors
Happell, Scholz et al. (2018)	"I don't think we've quite got there yet": The experience of allyship for mental health consumer researchers	J Psychiatr Ment Health Nurs	Australia	Qualitative	Consumers	Authors
Hards et al. (2022)	Actualizing community-academic partnerships in research: A case study on rural perinatal peer support	Res Involv Engagem	Canada	Research report	Consumers and the community	Researchers
Hawke, Sheikhan et al. (2022)	Embedding Lived Experience into mental health academic research organizations: Critical reflections	Health Expect	Canada	Research report	Consumers and carers, families, and supporters	Consumer researchers and authors
Hawke at al. (2023)	Research evidence and implementation gaps in the engagement of people with Lived Experience in mental health and substance use research: A scoping review	Res Involv Engagem	Canada	Review	Consumers	Authors, researchers

Authors	Title	Journal	Country	Design	Focus	Lived Experience roles (if identified)
Higgs et al. (2023)	Meeting in the middle: Experiences of citizenship in community-engaged psychosis research	J Public Ment Health	Canada	Research report	Consumers	Authors, researchers, Expert Advisory Group
Honey, Boydell et al. (2022)	Peer workers disseminating Lived Experience research: A perfect match?	J Ment Health Train Educ Pract	Australia	Qualitative	Consumers	Authors
Howard et al. (2001)	Training consumers to collect data in mental health service system evaluation research	J Psychosoc Nurs Ment Health Serv	US	Research report	Consumers	Unclear
Jakobsson, Genovesi et al. (2023)	Co-producing research on psychosis: A scoping review on barriers, facilitators, and outcomes	Int J Ment Health Syst	UK	Review	Consumers	Unclear
Jones, Callejas et al. (2023)	Barriers to meaningful participatory mental health services research and priority next steps: Findings from a national survey	Psychiatr Serv	US	Mixed methods	Consumers, carer, and community providers	Consumer-led project
Kennedy, Gunn et al. (2023)	Co-designing a peer-led model of delivering behavioural activation for people living with	Aust J Rural Health	Australia	Qualitative	Consumers - farmers	Advisory group

Authors	Title	Journal	Country	Design	Focus	Lived Experience roles (if identified)
	depression or low mood in Australian farming communities					
King at al. (2019)	Bringing together coproduction and community participatory research approaches: Using first person reflective narrative to explore coproduction and community involvement in mental health research	Health Expect	UK	Narrative	Consumers - CALD	Unclear
Knowles, Morley et al. (2023)	Collaborative evaluation of a pilot involvement opportunity: Cochrane Common Mental Disorders Voice of Experience College	Health Expect	UK	Qualitative	Consumers	Researchers, unclear if authors
Knowles, Sharma et al. (2022)	Adapting a codesign process with young people to prioritize outcomes for a systematic review of interventions to prevent self-harm and suicide	Health Expect	UK	Qualitative	Young consumers	Unclear

Authors	Title	Journal	Country	Design	Focus	Lived Experience roles (if identified)
Kruzan, Meyerhoff et al. (2021)	Centering Lived Experience in developing digital interventions for suicide and self-injurious behaviors: User-centered design approach	JMIR Mint Health	US	Research report	Consumers	None
Lambert et al. (2018)	'Outside the original remit': Co-production in UK mental health research, lessons from the field	Int J Ment Health Nurs	UK	Case Study	Consumers	Authors, consumer researchers
Lammers et al. (2004)	Research involving mental health consumers and carers: A reference group approach	Int J Ment Health Nurs	Australia	Research report	Consumers	Unclear
Lee, McKenna et al. (2023)	Strengthening mental health research outcomes through genuine partnerships with young people with lived or living experience: A pilot evaluation study	Health Expect	Australia	Mixed methods	Young consumers	Unclear
Li et al. (2022)	Mental health peer worker perspectives on resources developed from Lived Experience research findings	Int J Env Res Pub He	Australia	Mixed methods	Consumers	Consumer peer workers and research team

Authors	Title	Journal	Country	Design	Focus	Lived Experience roles (if identified)
Matheson et al. (2021)	Research and recovery: Can patient participation in research promote recovery for people with complex post-traumatic stress disorder, CPTSD?	Health Expect	UK	Qualitative	Consumers - CPTSD	Consultation via "engagement groups"
McCauley et al. (2017)	Service user engagement: A co-created interview schedule exploring mental health recovery in young adults	J Adv Nurs	UK	Qualitative	Consumers	Researchers
Milroy, Kashyap et al. (2022)	Co-designing research with Aboriginal and Torres Strait Islander consumers of mental health services, mental health workers, elders, and cultural healers	Aust J Rural Health	Australia	Qualitative	Aboriginal and Torres Strait Islander consumers and community members	Indigenous led, consultation with consumers
Morse, Forbes et al. (2019)	Australian mental health consumer and carer perspectives on ethics in adult mental health research	J Empir Res Hum Res Ethics	Australia	Qualitative	Consumers, carers, families and supporters, and Lived Experience researchers	Consumer researchers

Authors	Title	Journal	Country	Design	Focus	Lived Experience roles (if identified)
Pinfold, Clark et al. (2015)	Co-production in mental health research: Reflections from the People Study	Ment Health Rev	UK	Research report	Consumers and carers, families, and supporters	Consumer led project
Sangill et al. (2019)	Service user’s actual involvement in mental health research practices: A scoping review	Int J Ment Health Nurs	Denmark	Scoping Review	Consumers	Unclear
Scholz et al. (2019)	'There's just no flexibility': How space and time impact mental health consumer research	Int J Ment Health Nurs	Australia	Qualitative	Consumers	Researchers
Scholz, Happell et al. (2021)	People just need to try it to be converted!': A picture of consumer mental health research in Australia and New Zealand	Issues Ment Health Nurs	Australia	Quantitative	Consumers	Researchers
Scholz et al. (2019)	Very useful, but do carefully: Mental health researcher views on establishing a Mental Health Expert Consumer Researcher Group	J Psychiatr Ment Health Nurs	Australia	Quantitative	Consumers	Researchers

Authors	Title	Journal	Country	Design	Focus	Lived Experience roles (if identified)
Sharmil, Kelly et al. (2021)	Participatory Action Research-Dadirri-Ganma, using Yarning: Methodology co-design with Aboriginal community members	Int J Equity Health	Australia	Research report	Indigenous consumers	Consultation
Sheikhan, Kuluski et al. (2023)	Exploring the impact of engagement in mental health and substance use research: A scoping review and thematic analysis	Health Expect	Canada	Review	Consumers	Consumers were engaged in screening and designing the search strategy
Sinclair et al. (2023)	Inclusion as assimilation, integration, or co-optation? A post-structural analysis of inclusion as produced through mental health research on peer support	J Ment Health	Australia	Scoping Review	Consumers	Authors
Slade et al., (2016)	Developing involvement during a programme of recovery research	J Ment Health Train Educ Pract	UK	Qualitative	Consumers and carers, families, and supporters	Advisory group, which was one of five advisory groups on the broader research project
Thai, Sharif et al. (2021)	A Participatory Action Research (PAR) exploratory	Psychosis	Canada	Mixed methods	Consumers who	Unclear

Authors	Title	Journal	Country	Design	Focus	Lived Experience roles (if identified)
	initiative for psychosis recovery and resilience				experience psychosis	
van Draanen, Jeyaratnam et al. (2013)	Meaningful inclusion of consumers in research and service delivery	Psychiatr Rehabil J	Canada	Qualitative	Consumers - homeless	Junior researchers consulting on the conduct of the research and completing some research tasks
Vescey, Yoon et al. (2022)	A return to Lived Experiencers themselves: Participatory action research of and by psychosocial Clubhouse members	Front Psychol	US	Qualitative	Consumers	Researchers, trained and overseen by non-consumer researchers to engage in every part of the study including write up and study design
Videmšek and Fox (2017)	Exploring the value of involving experts-by-experience in social work research: Experiences from Slovenia and the UK	Eur J Soc Work	Slovenia	Autoethnography	Consumers and carers, families, and supporters	Consumers were involved as advisors on the PhD studies of the authors
Viksveen, Cardenas et al. (2022)	Involvement of adolescent representatives and co-researchers in mental health research: Experiences from a research project	Health Expect	Norway	Qualitative	Youth consumers	Youth consumers as authors and researchers

Authors	Title	Journal	Country	Design	Focus	Lived Experience roles (if identified)
Watson, Burgess et al. (2023)	A qualitative study exploring the benefits of involving young people in mental health research	Health Expect	UK	Qualitative	Young consumers	Authors, researchers
Worsley et al. (2022)	A qualitative evaluation of coproduction of research: 'If you do it properly, you will get turbulence'	Health Expect	UK	Qualitative	Consumers and carers, families, and supporters	Research working group

Appendix 4. Included peer reviewed publications

	Title	Country	Framework, strategy, action plan (etc)	Related domains: i) barriers and enablers; ii) good effective and active involvement; iii) research capacity building; and iv) future opportunities.	Consumer input (if known)
Bellingham et al. (2022)	CMHDARN - Co-production kick-starter	Australia	Guide	Barriers and enablers: people with Lived Experience may have had traumatising interaction with the health system; power dynamics; co-production takes time; communication needs to be adapted; diversity within project team Good effective and active involvement: decision-making power is shared through all stages of the research process; research is led and owned by Lived Experience researchers Research capacity building: seeking external training and support	Consumers involved through the Consumer Led Research Network (CLRN)

Katterl, Lambert et al. (2023)	Not before time report: Lived experience-led justice and repair	Australia	Report	Good effective and active involvement: they used a ‘berry picking’ model; grey literature contains greater consideration of Lived Experience voices and perspectives; interviews included Lived Experience and clinical voices; separation of facilitators and project facilitators	Consumers and carers involved as authors
Leading the Change Consumer Worker Action Group (2020)	Leading the change	Australia	Report	Good effective and active involvement: co-produced research including academics and Lived Experience; leadership of consumers; consumers were involved in interviews and analysis Research capacity building: training for emerging consumer researchers Future opportunities: address gaps in research around the experiences of consumer workers – this must be consumer-led research	Led by consumers
National Health and Medical Research Council (2018)	Keeping research on track: A companion document to ethical conduct in research with Aboriginal and Torres Strait Islander	Australia	Guide	Barriers and enablers: approach research with strong diversity and values; recognition of individual’s rights about active participation in research; mutual responsibilities of participants and researchers; the importance of research being translated in ways that are meaningful and that will	Unclear

	People and communities			have benefits for Aboriginal and Torres Strait Islander people Good effective and active involvement: build relationships especially in Aboriginal and Torres Strait Islander organisations and communities; work with communities to develop the research idea, the research proposal needs to be agreed on by the community; work ethically to collect data - make sure there is community understanding on data findings; present to community first; learn from the experience Research capacity building: train Aboriginal and Torres Strait Islander people in data collection	
National Mental Health Consumer and Carer Forum (2021)	NMHCCF perspective on Lived Experience and mental health research	Australia	Discussion Paper	Barriers and enablers: if participation is done poorly people with Lived Experience can feel unheard and marginalised; sharing of power; organisational structures Good effective and active involvement: good planning; training for Lived Experience; assigning a research mentor; clear communication and support	Consumers and carers involved as authors

				Research capacity building: specific funding of projects; establish a Lived Experience clearinghouse	
National Eating Disorders Collaboration (2019)	Developing a peer workfroce for eating disorders: Exploring the Evidence	Australia	Paper as part of a suite of resources	Good effective and active involvement: the process used was research, then consultation, then co-development; survey as well as literature search; interviews with peer and non-peer staff Research capacity building: established expert advisory group across the sector	Led by a consumer reseracher
NSW Ministry of Health – Experience Team (2023)	All of us	Australia	Guide	Good effective and active involvement: ensure accessibility and welcome; offer recognition; increase diversity and inclusion; be honest and keep people informed; use power in partnership; create and maintain safety	Consumers, carers, and community members
Our Future Project Partnership (2021)	Our future: developing introductory training for the Lived and Living Experience workforces in Victoria	Australia	Report	Barriers and enablers: recognition that different Lived Experience workforces (consumer and carer) are distinct; Lack of Lived Experience workforce-led research Future opportunities: support investment in Lived Experience-led workforce research; theoretical research to provide the infrastructure to	Led by people with Lived Experience – Consumers and carers,

				incorporate into training; mental health consumer workforce need research to explore work experiences; carer, family, supporter workforces need research to support the development of the disciplinary perspective; alcohol and other drugs consumer workforce research is required for the two distinct disciplines – lived and living; research should be conducted into how multiple lived and living experiences shape peoples' work; Research into unique needs into regional workers could be explored	families and supporters
Paino, River et al. (2023)	Towards a meaningful evaluation framework for peer work	Australia	Framework	Good effective and active involvement: the project team targeted peer workers from diverse social and cultural backgrounds; this framework does not prescribe how data is collected or used, rather it points to the meanings that can be explored	Led by peer workers
Rising Together Action Group (2022)	Rising together	Australia	Report	Barriers and enablers: training in co-production Good effective active involvement: carers, families and supporters, family and supporters are involved at all stages of the research – the research problem was decided by people with Lived Experience;	Led by Lived Experience, carers, families

				power differentials were acknowledged and addressed; Lived Experience academics led the Lived Experience workers; diverse work experiences and contexts were sought when selecting the Lived Experience members; there was a provocateur who asked curious questions Research capacity building: training in co-produced research; Lived Experience leadership and capability is developed Future opportunities: address gaps in research topics impacting carer, family, supporter workers	and supporters and consumers
Roper, Grey and Cadogan (2018)	Co-production: Putting principles into practice in mental health contexts	Australia	Framework	Barriers and enablers: power differentials; consumers lead at all stages Good effective and active involvement: decision-making is shared at all stages; co-production is different to participation, power imbalances are addressed Research capacity building: opportunities for capacity building; unique perspectives when compared to clinical and academic research	Consumers as authors

VMIAC (2023)	Brief guide to Lived Experience engagement in research	Australia	Checklist	Good effective and active involvement: Lived Experience experts in our own lives; our right to self-determination and information; recognising diversity; autonomy and choice; fair remuneration; ethical research practices; trauma-informed research	Led by consumers
VMIAC (2023)	Doing trauma-informed research with people with Lived Experience	Australia	Checklist	Good effective and active involvement: involving Lived Experience as experts in our own lives; being safe, ethical and responsible	Led by consumers
VMIAC (2023)	Lived Experience principles checklist	Australia	Checklist	Good effective and active involvement: acknowledgement and respect for Lived Experience expertise; diversity of Lived Experience is acknowledged; fair remuneration; trauma-informed research design; the research question has been identified as a priority by people with Lived Experience	Led by consumers
VMIAC (2023)	Research participant checklist	Australia	Checklist	Good effective and involvement: active acknowledgement and respect for Lived Experience expertise; diversity and inclusive practices; fair payment; ethical and safe research	Led by consumers

VMIAC (2023)	VMIAC research strategy	Australia	Strategy	Barriers and enablers: building the profile of Lived Experience research and evaluation Research capacity building: design and develop consumer-led research; Lived Experience PHD scholarships Future opportunities: building the profile of Lived Experience research; fund research partnerships with Lived Experience researchers; strengthen research networks; Lived Experience knowledge translation; provide opportunities for consumers to be involved in research; build partnerships	Led by consumers
Webb, Cooper et al. (2023)	Guidelines for involving young people with Lived and Living Experience of suicide in suicide research	Australia	Guidelines	Barriers and enablers: concerns of potential adverse effects Good effective and active involvement: staffing resources need to be considered; equitable recruitment of diverse people; help young people determine their ‘readiness’; onboarding and training; create safe environments; safety strategy; evaluating involvement Research capacity building: involve young people in designing studies and ethics applications; data analysis; dissemination	Led by Lived Experience youth advisors