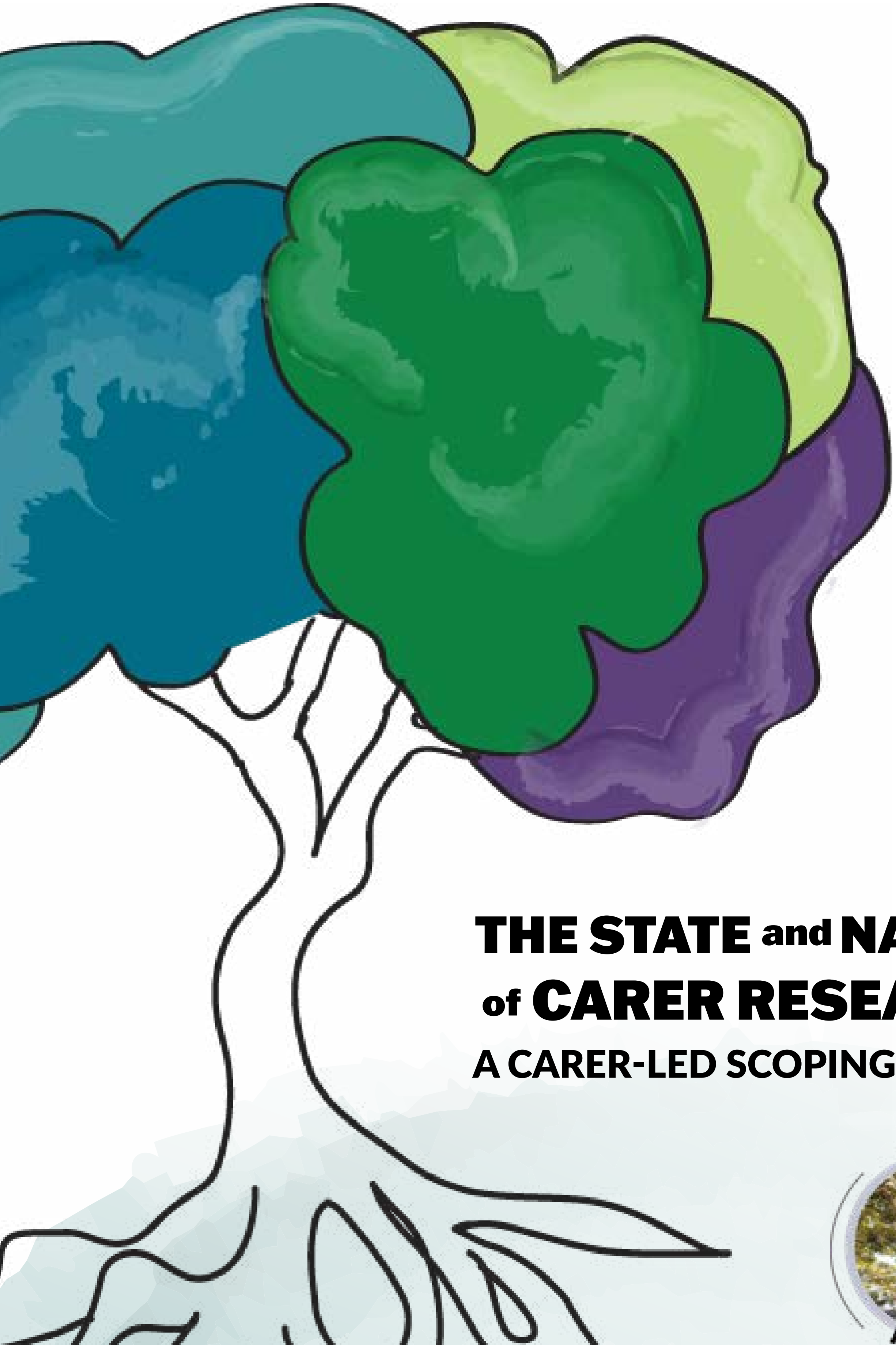


THE STATE and NATURE of CARER RESEARCH

A CARER-LED SCOPING REVIEW

FaCRAN

> “...there’s a responsibility here for researchers and universities if they want lived experience research, to advocate that [family carer inclusion] gets done efficiently, and they've got a responsibility that they’re doing that right, and I think we should be doing this as a joint partnership together...”

A family and carer led report produced by FaCRAN and RMIT for the Victorian Collaborative Centre for Mental Health and Wellbeing.

Photo of tree by
Jeremy Bishop
www.jeremybishopphotography.com

ACKNOWLEDGEMENT OF COUNTRY

This family and carer-led research review project was commissioned and conducted from the sovereign lands of the Bunurong, Woirrung and Wurundjeri People of the Kulin Nation. Additionally, family carer participants joined us from the many Aboriginal and Torres Strait Island lands from around the Nation.

The authors of this study want to acknowledge that First Nations Peoples have complex and sophisticated kinship systems and relational networks, where people might belong to each other, to other peoples, to places and to country. For the non-Aboriginal authors of this research, we collectively recognise that the responsibility to support, and learn from, First Nations' kinship wisdom sits with us.

SUGGESTED CITATION

Lambert, C., Alvarez, A., Martin, R., David, C., Nipperess, S., Schnioffsky, B., Walters, C., Petrakis, M. (2024) Mental Health Family and Carer Research Scoping Review, Victorian Collaborative Centre for Mental Health & Wellbeing.

REPORT OWNERSHIP AND LANGUAGE

At its core, this study belongs to the family carers who led, co-created and contributed to it. Any impact or benefit from the research should prioritise the families, carers and kin who are supporting people experiencing social determinants of despair, or mental ill health.

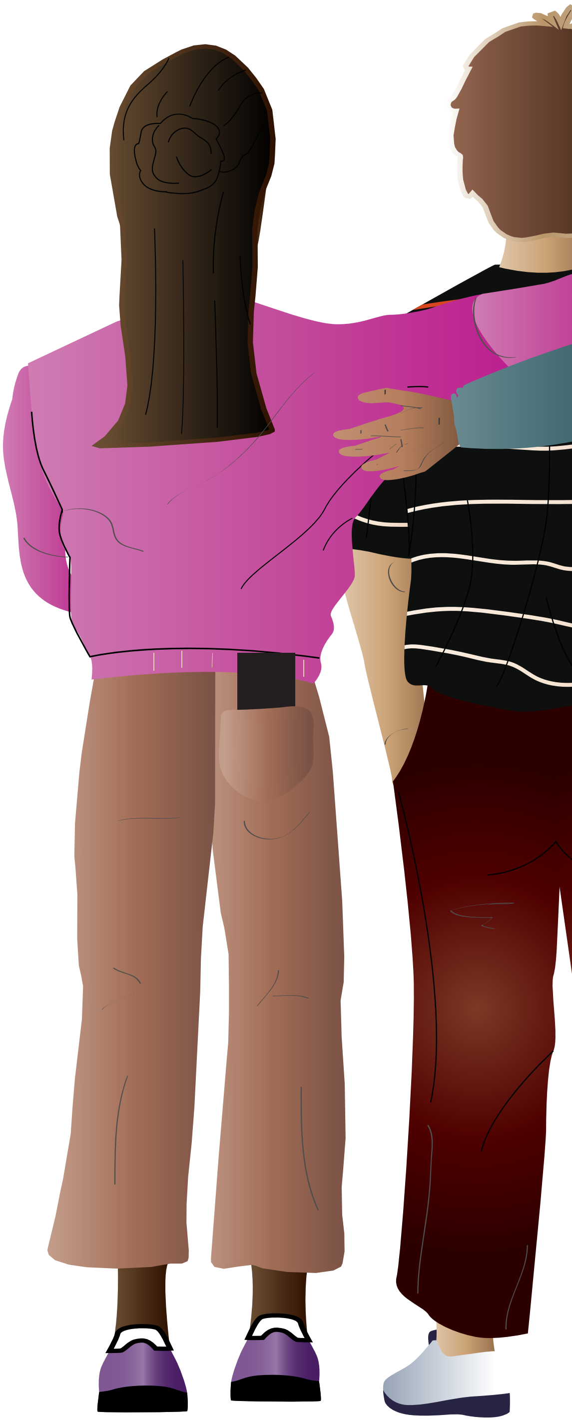
Where there are quotes in this report, we have replaced the term ‘participant’ with ‘family carer collaborator’, to reflect a shift from passive to active positioning of carer co-creators. We gratefully acknowledge the perspectives and insights of family carer collaborators, while also respectfully recognising that these contributions do not capture everyone’s unique experiences of supporting someone.

In this report, the descriptors ‘family’ and ‘carer’ are used interchangeably with ‘kin’, ‘supporter’ or ‘friend’, in recognition that labels are contested, dynamic and contextual. Similarly, the terms ‘consumer’ and ‘service users’ are used interchangeably. When using the term ‘family’, the authors include family of choice. A glossary of terms can be found in the Appendix of the report.

PROJECT TEAM

This research project is unique in the current research landscape, as it has been led by a collective of family carer researchers. Dr Caroline Lambert is a carer academic who has led the project alongside other FaCRAN founding members, Amaya Alvarez, Dr Christina David, Professor Robyn Martin, Associate Professor Sharlene Nipperess, Associate Professor Melissa Petrakis and Caroline Walters. Broader FaCRAN membership were also integral to the research design and content. This project was ably assisted by Dr Bess Schnioffsky.

The VCCMHW project team included Dr Katie Jones, Dean Kovolos and Nicki Moseby. In the spirit of ‘doing things differently’ and being ‘unapologetically ambitious’ in collaboration, the VCCMHW research team were involved in key elements of the research process. Thank you for coming on the journey with us.



SUMMARY

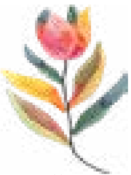
BACKGROUND

People with lived and living experiences of supporting one or more people with psychological distress were recognised as a key group who were concurrently poorly supported, excluded, underappreciated and capable of leading vital system transformation during the 2019 Royal Commission into Victoria's Mental Health System (RCVMHS). Through the Commission's Final Report (2021), family, carers or supporters, would be earmarked both for assisting in reform, as well as gaining much needed support, through numerous mechanisms and levers. One such mechanism could be found in family carer participation, content focus, and co-production of contemporary research.

This mental health family and carer research scoping review is a family carer-led study commissioned in December 2023 by the Victorian Collaborative Centre for Mental Health and Wellbeing. The VCCMHW notes that "we will drive ground-breaking change to Victoria's mental health and wellbeing system, so that people receive mental health and wellbeing support when, where and how they may want it" (Victorian Government, 2024). The Centre uses the evidence of lived experience as the basis for adult and older adult service design, delivery, research, research translation and evaluation.

The study, which was conducted by the Family and Carer Research Advocacy Network (FaCRAN) at RMIT University, sought to illuminate and understand the state and nature of family carer research, firstly in Victoria and then more broadly. FaCRAN is an established, Victorian based, Australia-wide network of family carer perspective researchers, family carers, and researcher allies. The project questions and aim were driven by the findings from the RCVMHS (2021), which identified eleven research priorities and opportunities for innovation. This scoping review focused on research theme priority number five; families, carers and supporters. As set out in the final Royal Commission report:

"The future system will respond to the significant role that relationships of care and support play in promoting mental health and wellbeing for people living with mental illness or psychological distress. Research will provide a stronger understanding of the crucial role that parents, families and other carers and supporters play, the challenges they face, and how their experiences can strengthen how services are offered and delivered. It will also inform the development of dedicated supports that the system will offer to families, carers and supporters" (RCVMHS, 2021, p. 181).



"Research will provide a stronger understanding of the crucial role that parents, families and other carers and supporters play..."

APPROACH

What is the state and nature of contemporary family carer research?

The approach for this study included a scoping review (SR) of peer reviewed and grey literature related to mental health carers, as well as family carer collaborator dialogic consultations, conducted through focus group and 1-1 interview methods.

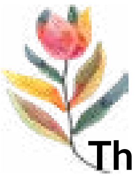
The SR was guided by the five step framework provided by Arksey and O'Malley (2005). A total of 152 peer reviewed papers and 46 grey literature sources (total = 198) were included in the review, and 18 family carer collaborators were consulted through the focus group and 1-1 interviews. The consultations were run from Victoria, and included carers across four Australian States, based in regional and metropolitan locations. Family carer collaborators were identified through FaCRAN membership, and invited to participate, by sharing their perspectives, expertise, experiences and opinions on the state and nature of contemporary family carer research.

Data produced through the consultations was coded and thematised using the six phased thematic analysis approach of Braun and Clarke (2006). Researchers then synthesised what was found in the scoped literature, with the themes arising from the conversations with family carer collaborators, providing opportunities or recommendations which will allow the VCCMHW to build family and carer research that is inclusive, useful and expansive.

KEY FINDINGS

A summary of findings include;

- Only 4% of the 152 peer reviewed studies were identified as authored by carer experts, who were writing explicitly from their lived experience.
- 11% of peer reviewed literature included carers having involvement in multiple elements of research design (i.e. methodology or conceptual framing) and process (i.e. data collection, analysis) but were excluded from recognition in authorship.
- 7% of carer focused peer reviewed research did not include any carer participants.
- 57% of research papers had carer only participants.
- 28% of the peer reviewed articles were published in health focused journals, including occupational therapy, health practice or health promotion.
- Psychiatric and psychological journals published 21% of family carer focused papers.
- 37% of the peer reviewed literature focused on how services should or could include carers in family delivery.
- 24% of peer reviewed papers focused on experiences of caring or carer wellbeing.
- 13% of peer reviewed papers focused on carers supporting people with a particular diagnosis (often psychosis).
- 43% of the 46 pieces of grey literature were produced by Commissions or government departments such as the Queensland Mental Health Commission or the National Mental Health Commission, 17% were produced by service providers such as MIND Australia and 15% were driven by family carers or family carer workforce, such as the Carer Lived Experience Workforce (CLEW).
- Grey literature primarily focused on providing information for service providers working with families, service or program evaluations or lived experience workforce frameworks or strategies.



Thematic analysis of the family carer collaborator consultations produced three key themes related to the state and nature of family carer research.

THEME 1

BARRIERS FOR FAMILIES AND CARERS IN RESEARCH

- Participation in and opportunities to lead research are often limited by the invisibility of family carer researchers - ‘you can’t be what you can’t see.’
- Limited educational or vocational pathways for family and carer researchers who want to get into research.
- Funding that is driven by the agendas of others; clinical and individualised views of mental health and a lack of funded spaces that are prioritising family and carer research.
- Inadequate funding to allow for ‘slow research’ that is needed to accommodate for the intensity or unpredictability of family and carer role.
- Research mirrors how systems position families and carers as unpaid contributors to the sector.
- Marginalisation - “Why bother”? Lack of accessible translation and dissemination, means that there is sometimes an unclear return for effort.

THEME 2

QUALITY OF FAMILY CARER RESEARCH

- Missing intersectional foci such as research which includes alcohol or other drugs or forensic mental health.
- Research is missing or ignores the complexity of the carer experience.
- Limited research design that doesn’t allow for inclusion and collaboration with family and carer folk.
- Historic lack of opportunities for family carer research leaders.
- Absence of research related to, and driven by young carers.
- Limited conceptual framing of family and carers, that often overlooks the social determinants of distress.

THEME 3

ENABLERS OR FACILITATORS OF GOOD FAMILY CARER RESEARCH

- Strong allies across disciplines.
- Prioritising upskilling for families and carers who are interested in leading or en-gaging in research.
- Power sharing between academic researchers and those who sit out the academy, or don’t have roles or positions of authority.
- Researchers taking time to get to know the family carers they are working with.
- Using contemporary language in research.
- Providing safety to family carers in the research process.
- Research that is aligned with family carer advocacy goals, or which contributes to building advocacy or change.
- Building trust between re-searchers and lived experience collaborators.
- Using participatory methodologies, being included throughout the research process.

OPPORTUNITIES: VICTORIAN COLLABORATIVE CENTRE for MENTAL HEALTH & WELLBEING

Combining the results of the scoped literature with the themes from the family carer consultations, the key opportunities related to family carer research for the Victorian Collaborative Centre for Mental Health and Wellbeing include:

PRIORITISE AREAS, DEVELOP & RESOURCE

TIMELINES	ACTION
Immediate-ongoing	• Prioritise the funding of a First nations-led research framework for and implementation of research projects exploring Indigenous frameworks and collective community responses to distress, relating to family carer context. Consider how learning might be respectfully supported and shared across all current research practice and responses.
Immediate-ongoing	• Develop, foster and fund young carers research group(s), and ensure that there is a "baked-in mentoring" that occurs within all research projects
Immediate-ongoing	• Fund more inclusive pathways for families and carers co-lead research. This might include micro-credentialling (which needs to be developed), funding, scholarships, or research stipends that financially support carers back into study.
Immediate-ongoing	• Build family carer researcher allies across other organisations that can partner with, co-plan and co-lead family carer research opportunities.
Immediate-ongoing	• Ensure carers co-lead VCCMHW research that is both related to care giving, as well as not directly related to their identified role.
Immediate	• Prioritise funding of research that investigates the unique experiences, needs, as well as innovative support solutions for regional, rural and remote Australian mental health carers
Immediate	• Prioritise funding of research that is lead or co-lead by CALD carers.
Immediate-ongoing	• Support and resource small, deep ponds of family carer research, rooted in community, connected to people, place and location. ...create pockets and work really deeply, relationally and have some really good stuff happen and then encourage others, or others might be motivated to do something different through seeing what's happening in that space.

WAYS TO ENGAGE

TIMELINES	ACTION
Immediate-ongoing	• Fund and prioritise carer projects that allow for 'slow research' ensuring generous or expansive timelines.
Immediate	• Fund lived experience (carers and consumers) researchers to co-produce new mechanisms for procuring their services - focusing on ensuring collaboration not competition.
Immediate	• Lead system change by using inclusive or transformative definitions of expertise, knowledge and research in the VCCMHW research strategy, clearing house and other research functions.
Immediate-ongoing	• Prioritise research that focuses on care giving, using a critical framing that includes all the social determinants of wellbeing and despair, rather than a purely biomedical framing. Poverty, genocide and war, refugee and immigration, gender and sexuality, alcohol and other drugs, and correctional or justice need to be prioritised as intersectional experiences.
Immediate-ongoing	• Prioritise funding projects that use participatory frameworks, orientation or methodologies. ***It would be excellent to have more co-produced research, more lived experience led research.***
Mid-term	• Prioritise (fund, showcase and embed learnings into VCCMHW research & service delivery) projects that promote greater understanding of how power operates and impacts family carers, and carer workforce within mental health and research eco-systems, as well as reform spaces. ***How do you address power? How do you respond when what one group wants might negatively impact another group and how do you hold that in the group when there are different positions which might be painful for some people to hear?***

WAYS TO TRANSLATE & DISSEMINATE

TIMELINES	ACTION
Immediate	• Ensure family carer researcher perspectives are central to any VCCMHW translational and dissemination research strategies or functions.
Immediate	• Utilise the co-designed ‘good research’ guidelines for researchers and carer participants, which include information on keeping carer participants ‘in the loop’ with research impact (see Appendix 4)
Immediate-ongoing	• Fund carer and carer researchers to develop mechanisms and clear guidelines that ensure carer author attribution.
Immediate-mid term	• Partner with existing metropolitan and rural, regional and remote family carer research ponds to collaborate on research, knowledge and practice translation and dissemination.
Immediate–mid-term	• Host or co-host research seminars, conferences, or forums which plat-form contemporary carer-led research.
Mid-long term	• Consider building VCCMHW translation functions similar to Yale University’s technology transfer hubs, enabling innovative family carers ideas to be converted into new, evidence-based practice approaches

OPPORTUNITIES & RECOMMENDATIONS RELATED TO CARER FOCUSED & INCLUSIVE MENTAL HEALTH SERVICES

CONCERNS OR BARRIERS TO CARER FOCUSED & INCLUSIVE SERVICES	SUGGESTED STRATEGIES FOR SERVICE
Interactions between clinicians and carers are not always respectful or helpful for carers (McCann & Bamberg, 2016; Kaselionyte et al., 2019). Carers need more resources and psychosocial spiritual support, sometimes for their own needs, but also in relation to the person they support. Lack of service support for carers supporting someone using antipsychotic medications (Morrison & Stomski, 2017, 2018) as well as lack of support, advice or advocacy for carers supporting someone who is detained for involuntary treatment (Rugkåsa & Canvin, 2017).	Ensure clear, co-designed policies related to access, engagement and support for family, carers and supporters. Consider the co-designed 'Working with Families Training' from Tandem. Also follow the Victorian Office of the Chief Psychiatrist (OCP) 'Working Together with Families' Guidelines (2018). The OCP guideline has a useful self-audit tool for mental health organisations. Provide carer peer support and advocacy services (Mercuri et al., 2022, Rising Together, 2022). Offer support which is dialogically based. Provide emergency and respite funding for families and carers, on top of what is currently available through the Carer Support Fund (CSF).
Carers sometimes experience caring-related trauma (Tandem Carers, 2023)	Ensure trauma informed care is available for carers.
Carers are sometimes excluded from information as staff are unsure of the legislation on sharing information.	Provide training for staff on interpreting confidentiality and privacy policies and legislation
Young carers are often not recognised and included by service providers (Hameed et al.,2023).	Identify and include young carers in treatment plans. Ensure staff are aware of and connected with the Satellite Foundation.

CONCERNS OR BARRIERS TO CARER FOCUSED & INCLUSIVE SERVICES	SUGGESTED STRATEGIES FOR SERVICE
Carers (and services) are sometimes unclear about the rights of family, carers and supporters.	Invest in research, legislation and proactive education and advocacy on carer rights.
Recovery models must include recovery for family carers (Fox J, 2022; Fox et al., 2015; Hungerford & Richardson, 2013; Israel et al. 2023, Poon et al., 2018).	Facilitate consensus amongst staff on including families and relationality in the concept of recovery. Consider co-developed training on family and carer recovery.
Measurement tools do not always capture what is useful for carer related service improvement (Maybery et al., 2021, 2022).	Use measurement instruments that are developed by carers.
Lack of understanding from services on care giving within the context of collectivist cultures (Magan et al., 2022). Hyper-individualised mental health service responses can alienate and harm family, carers, supporters and communities.	Build practices and responses that are culturally inclusive and safe. Consider a transnational collectivist approach to service delivery particularly for migrant and refugee populations (Magan et al., 2022). Extend the model of recovery to include relational recovery, family unit and collective recovery.
Discrimination and stigma may be internalised with power dynamics not always being overt or easily identified by carers (McNeil, 2013). The reason behind the experienced stigma may be multilayered (Mignone et al., 2018; Sawrikar & Muir, 2018).	Foster a culture of resistance by cultivating a critical awareness for carers of dominant discriminatory attitudes and practices. This culture might also feed into a co-designed program of carer rights awareness raising, advocacy and education or training.

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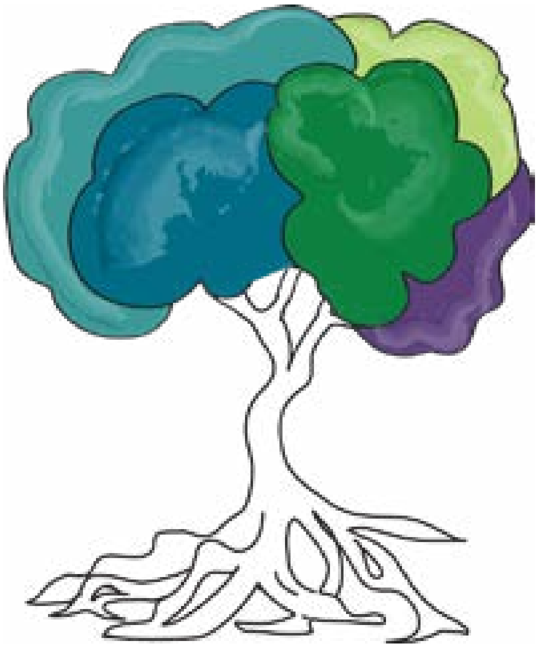


LIST OF ACRONYMS

CLEW	Carer Lived Experience Workforce
CMHL	Centre for Mental Health Learning
FaCRAN	Family and Carer Research Advocacy Network
FC	Family Carer
FGD	Focus Group Discussion
NMHCCF	National Mental Health Consumer and Carer Forum
RCVMHS	Royal Commission into Victoria’s Mental Health System
RANZCP	The Royal Australian and New Zealand College of Psychiatrists
SR	Scoping review
VCCMHW	Victorian Collaborative Centre for Mental Health and Wellbeing

VICTORIA & THE RCVMHS RECOMMENDATIONS for FAMILIES & CARERS

Who are we & what defines families & carers in this context?

The recent RCMVHS (2021) demonstrated that all people exist within a relational context, and that thoughtful and planned family and carer inclusion in mental health services is vital to ensuring better outcomes for everyone, including consumers (Day & Petrakis, 2016). However, there are few adequately funded studies into the lived experience of family carer contributions and other areas of everyday need for families and carers (Doody et. al., 2017; Ewertzon & Hanson, 2019; Walters & Petrakis, 2022; Walters & Petrakis, 2023). Where studies have been funded to support family carers, they are often categorised as having low methodological quality, poorly identified interventions that do not focus on supporting the carer, or trials that failed to account for the increasing complexity of service and care environments (Lobban et al., 2013; Yesufu-Udechuku et al., 2015).

Given the significant contribution that families and informal carers make in supplementing funded mental health services, and the fact that families and carers are often facing their own mental health and wellbeing challenges (Myleck & Shirmer, 2023), there is a demonstrated need for further carer led and driven research. Moreover, existing research that investigated positive impacts of embedding carers within a research process, found that the carers in a UK research project, had a universally positive impact on the family carers involved, the (non-carer) researchers, as well as being able to attribute "small positive impacts on mental health services and related services" to the co-produced study (Kara, 2018, p. 88).

The RCVMHS (2021) not only outlined the need for family carer inclusion, but also spoke to the need for lived experience centred reform, and that both require an evidence base. Building on the United Nations International Year of Disability 2004 motto '*nothing about us without us*' this scoping review honours new ways of working with lived experience. In a family carer research frame, this means that research is inclusive of families and carers and led by lived experience family carer innovators and mentors.

This approach has been advocated for, and adopted in the consumer lived experience research space and this scoping review will encourage and prioritise emerging research leadership in the community of family and carer with lived experience expertise. Carer lived experience expertise builds and promotes approaches to research that centre collaboration, co-design, relational wellbeing and carer rights.

This includes the:

- capacity to understand the diversity and commonalities of family carer experience; and
- strong grass roots orientation and networks of families and carers; and
- capacity to translate these experiences into a shared language and different decision-making settings; and
- engagement with policy and advocacy work that speaks to the concerns, challenges and experiences of families and carers.

This section outlines the methods used to help answer the overarching research question of *'What is the state and nature of family carer research?'*

This project consisted of two distinct research methods, which focused on identifying experiences of participating in or leading carer research, types of current family carer-centric research, who is conducting and authoring the research, and in what context it is being conducted.

The first method, a scoping review (SR), involved scrutinising peer-reviewed and grey literature. The second method involved dialogic consultations (focus group and 1-1 interviews) with current and emerging family and carer perspective researchers.

METHOD 1: SCOPING REVIEW

The purpose of the SR was to better understand the nature and extent of family and carer led, and/or focused, mental health and wellbeing research evidence in Australia, with a primary focus on material produced in or for the State of Victoria. The five-stage process outlined by Arksey and O'Malley (2005) guided the scoping review:

Stage 1: Identifying the research question
Stage 2: Identifying relevant studies
Stage 3: Study selection
Stage 4: Charting the data
Stage 5: Collating, summarizing and reporting the results.

To identify relevant studies, search terms were developed using the research question and RCVMHS research theme priority number five; families, carers and supporters, as a guide. Boolean strings were used to broaden the search and simultaneously maintain relevance to the research questions and focus. The search terms can be found in Table 1.

The search was primarily conducted by Dr Caroline Lambert, with assistance from Dr Bess Schnioffsky, and consultation at critical junctures of the process, from co-founding FaCRAN members, Professor Robyn Martin, Amaya Alvarez, Dr Christina David, Associate Professor Melissa Petrakis, Caroline Walters, and Associate Professor Sharlene Nipperess. Initially article titles and abstracts were screened against the inclusion and exclusion criteria in Table 3. with duplicates removed. All included articles were independently cross checked by two researchers (CL + BS) and then any articles that were considered borderline for inclusion were checked by two more team members (CD + NM). The PRISMA chart (Fig.1) outlines the scoping process.

After the studies had been selected for inclusion, the next phase was to chart the data, which was done by applying a descriptive analytical frame that described a set of information for each study, which included:

- Authors
- Article title
- Year of publication
- Journal name
- Method
- Participant cohort
- Carers integral to several key elements of research design (i.e. conceptual framing or methodology) and process; (i.e. recruitment or analysis) excluding authorship.
- Carer author attribution made explicit within the paper
- Country / region of focus
- Funding
- Findings or focus of investigation

While all of the 152 papers were scoped by reading titles, abstracts and conclusions; given the focus of this investigation, any papers that were charted as having carers leading or central to multiple elements of the research design and process, were then read (CL) in their entirety from abstract to conclusion.

The link to the Excel spread sheet record of the 152 peer reviewed studies and 46 grey literature items can be found here.

Grey literature was scoped using a modified version of Arksey and O'Malley's phases, with steps 2 and 3 differing. Documents were identified via professional network and a pdf. search on Google, with the same search terms and date range applied as per the peer reviewed search. Given timelines, and resource considerations, the selection was then limited to including the first page of yielded results.

TABLE 1: SEARCH TERMS

Population characteristics content and/or author
Famil* or Carer/*or Kin or Parent* or Supporters or Caregiver
+ Mental health or Mental Illness or Mental Health Challenges or Psych* or Mental distress
Population Context
+ Challenges or Exclusion or experience or perspective or support or inclusion

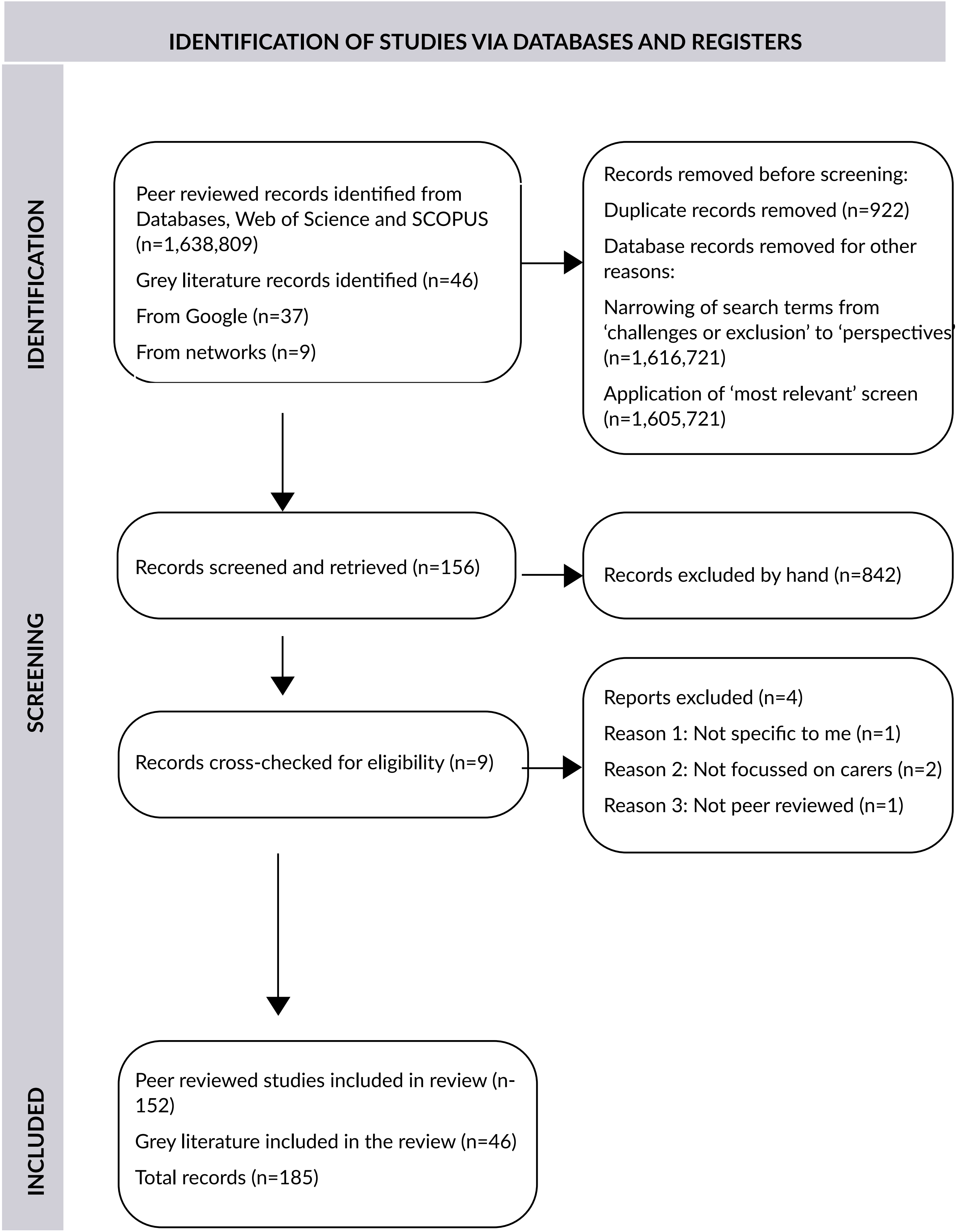
TABLE 2: LITERATURE REVIEW SEARCH STRATEGY TO IDENTIFY RELEVANT PEER REVIEWED STUDIES.

Search strategy
Databases
Hand searching through select journals or conference proceedings
Reference list checks
Utility of existing expert networks

TABLE 3: STUDY SELECTION

Criteria	Inclusion	Exclusion
Language	English	Other languages
Publication date	2013 - 2023	Prior to 2013
Publication type	Peer reviewed journals with abstract and non-peer reviewed, or ‘grey literature’. For this project, grey literature is material produced by government, academics, industry and business, which may be in electronic or print format.	Material that does not have a written abstract or executive summary
Location of publication	Australia & International	-
Content or author characteristics	Includes 2 population characteristics and 1 population context	-

FIGURE 1. PRISMA CHART



METHOD 2: DIALOGICAL CONSULTATIONS WITH FAMILY CARER RESEARCHERS

Dialogical (conversational) approaches to consultations were chosen both to honour relationality which often characterises family carer research(er) work, and to enable greater flexibility or choice of what information carer collaborators might contribute. Participants had the choice of meeting online or in person, and all chose to meet online.

Ethics approval (Project number 27279) was granted from the RMIT University Design and Social Context College Human Ethics Advisory Network (see Appendix 2).

Recruitment of family carers was done via the FaCRAN membership email. To join FaCRAN, members needed to self-identify as a family carer researcher, a carer interested in research, or a research ally to family carers. Plain language information and consent forms were sent to individuals who had responded to the recruitment flyer, with 15 family carers opting to attend the focus group. After the focus group was conducted 3 additional FaCRAN members who did not attend the focus group, were approached by CL or BS to contribute their unique perspectives.

The consultation approach was a mix of conversational focus group and semi-structured interviews (Swain & King, 2022; Liamputtong, 2010), which enabled reciprocal exchanges of knowledge and sharing of power, and recognition of the unique expertise of all participants.

Details of the focus group and interview guides can be found in the Appendix 3 of the report. All 18 of the family carer research collaborators were assigned a number, carers who participated in a 1:1 interview chose a pseudonym that can be used for other publications or presentations.

Details of the focus group and interview guides can be found in the Appendix 3 of the report.

The consultations supplemented the scoping review through engaging carer lived experience and expert insights, thereby delivering a more robust and nuanced commentary on the gaps in the research as well as identifying key family and carer research experiences , and the positioning of families and carers in contemporary work.

Carer research collaborator conversations included:

- FaCRAN members as a group (focus group method) and;
- FaCRAN members who did not attend the focus group, in a 1:1 interview.

To ensure diverse experiences and perspectives we included :

- Family carer researcher elders (people in a carer advocacy or research role for 10+ years)
- Non-academic persons with a demonstrated interest in family carer focused research
- Newly established/establishing young family carer researchers
- Intersecting consumer and carer perspectives, and associated perspectives.

The six steps of Braun and Clarke’s (2006) thematic analysis method were applied to the combined focus group and 1-1 interviews with families and carers, which allowed for themes to be generated, reviewed, defined and named.

The six steps of analysis included:

1. Become familiar with the data: CL and BS transcribed and de-identified the focus group and interviews, reading and re-reading the transcriptions.

2. Generic initial codes: CL systematically coded interesting features of the data across the entire data set.

3. Search for themes: CL generated or collated codes into potential themes, gathering all data (and quotes) relevant to each potential theme. Codes and potential themes were checked with focus group collaborators to ensure comfort levels with potential themes, accuracy and attribution of quotes to potential theme.

4. Review themes: Themes were reviewed and checked in relation to the coded extracts and the entire data set. In looking for a coherent pattern in themes an initial 11 potential themes were collapsed or reduced to 4, then finally 3. Authors CL, AA and CD were instrumental in re-organising of the themes.

5. Define themes: Defining the themes or capturing the "essence of what each theme was about" (Braun & Clarke, 2006, p.92). The final three themes were defined as: 1) barriers for families and carers in research; 2) quality of family carer research; and 3) enablers or facilitators of good family carer research.

6. Write up: Through analysis and synthesis of the various sources data generated by the scoping review, the focus group and the 1-1 interviews, FaCRAN researchers were able to identify the strengths, gaps, limitations and priorities related to the state and nature of family and carer developed and focused research evidence (Munn et al., 2018). Findings are explored in the next section.

Through analysis and synthesis of the various sources data generated by the scoping review, the focus group and the 1-1 interviews, FaCRAN researchers were able to identify the strengths, gaps, limitations and priorities related to the state and nature of family and carer developed and focused research evidence

The SR identified several key findings of the peer reviewed and grey literature. Author identity, discipline of journal, article topic, country of origin, funding, methodology, method, and participant details. Table 4 captures findings of the peer reviewed research papers.

TABLE 4. PEER REVIEWED PAPERS

DISCIPLINE OF JOURNAL	out of 152	% of 152
Health (including OT, Practice, Health Promotion)	43	28%
Psychiatric / psychological (including therapy)	32	21%
Nursing/care	31	20%
Social work	22	14%
Mental Health	19	13%
Social science /Law	5	3%

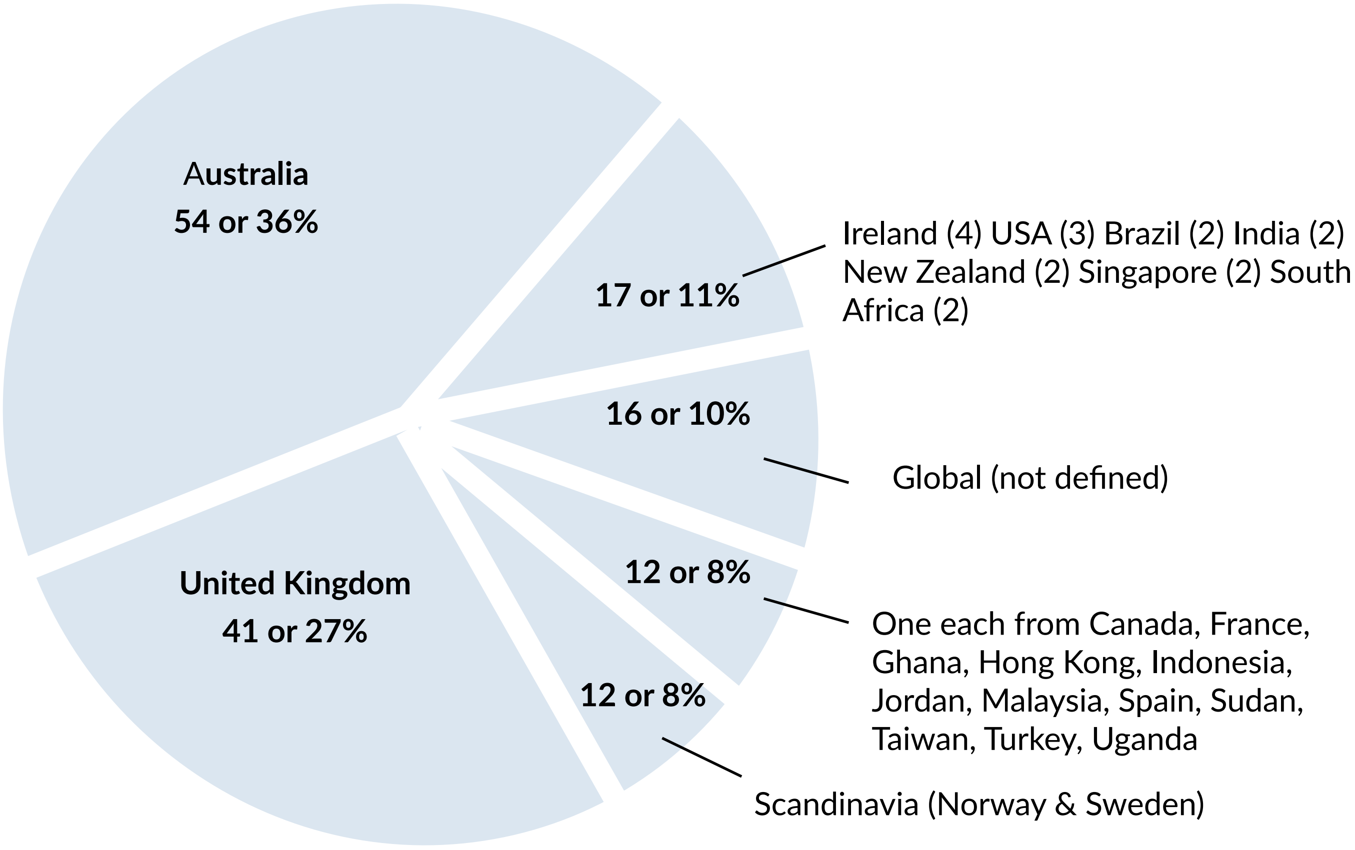
AUTHOR IDENTITY *Identified family carer researchers within the paper		
Family carer (made explicit in paper)	6	4%
Service user/consumer led	3	2%
Undefined or not explicitly stated	143	94%
Carers integral to multiple key elements of research design* (i.e., methodology, conceptual framing) and process (i.e., data collection, analysis) but excludes authorship recognition.	18	11%

ARTICLE TOPICS		
How services should or could include carers in service delivery	56	37%
Carer experience / perspective / wellbeing (one article explored rural carer experiences in an Australian context and one focused on rural Malay context)	36	24%
Family carers of people with specific diagnoses	20	13%
Community support of carers	13	9%
Family carers & communication	11	7%
Carers and legislation / research	7	5%
Stigma and family caring	6	4%
Covid-19 and carers	3	2%

SOURCE OF FUNDING		
Philanthropic trusts	7	5%
Mixed research / institutes / partnerships	36	23%
As part of a PhD	4	3%
No or undisclosed funding	105	69%

METHODOLOGY USED		
Quantitative	36	24%
Qualitative	101	66%
Mixed methods	11	7%
Commentary / reflection	4	3%

FIGURE 2: COUNTRY OF ORIGIN (OUT OF 152)



METHOD	out of 152	% of 152
Interviews (Only)	48	32%
Evaluation	8	5%
FGD (Only)	14	9%
FGD + Interviews/Written	11	7%
Questionnaires / Survey	28	18%
Interviews + Questionnaires	6	4%
Other (e.g., Auto-E, Commentary / Policy / Feasibility study / proposed models	16	11%
Review of literature	14	9%
RCT	4	3%
Large data sets analysis	3	2%

CHARACTERISTICS OF PARTICIPANT COHORT		
Triad (consumer/carer/professional)	6	4%
Professional + carer	8	5%
Professional (social worker, occupational therapist, psychiatrist)	7	5%
Consumer	3	2%
N/A (e.g., reviews or big data sets)	30	20%
Carers	86	57%
Dyad (consumer/carer)	12	8%

WHO IS PRODUCING THE PEER REVIEWED LITERATURE?

Most of the peer reviewed literature was authored by university affiliated academics located within social science, medical, health, social work or other allied health disciplines, together with clinicians who were practicing in mental health services. Three papers were identified as consumer/service user authored.

While all of the 152 papers were scoped by reading titles, abstracts and conclusions; any papers that were charted as having carers or carer researchers central to multiple elements of the research design, i.e. methodology, conceptual framing, and the process, i.e. data collection, analysis, were also read (CL) in their entirety from abstract to conclusion. Authorship institutional/discipline affiliations of all 152 papers were also charted. It was found that less than 4% (6) of all the 152 papers made explicit reference to one or more of the authors identifying as a family carer. Five of the six were Australian based papers.

WHAT ARE THE CHARACTERISTICS OF THE DATA COLLECTED ACROSS ALL LITERATURE?

In terms of methods employed by peer reviewed papers, there were few carer focused studies that generated primary data, and when they did so, the sample sizes were generally less than 20. Outliers to this trend was Brown (2023), who included a sample of 31, Lawn and McMahon (2015) who surveyed 121 carer participants. Petrakis and Walters (2023) whose study was picked up through the grey literature search, conducted focus groups and online surveys with 174 family members, friends, carers and supporters across Australia. However, larger research projects that did generate primary data were often thinly sliced into multiple publications based on the same data set . Examples of this include research by Poon et al. (2017, 2018), Sin et al. (2021, 2022), and Walters and Petrakis (2022) Walters et al. (2022, 2023).

Most of the papers used a qualitative approach. The most common research methods for data collection in the peer reviewed literature included 1:1 semi-structured interview, focus groups, questionnaires (often as part of a mixed methods approach), systematic and scoping reviews, as well as 3% of papers used randomized control trials (RCT).

There was a notable absence of diverse perspectives, with minimal intersections with race and ethnicity, class, other disabilities, age or identified sexualities. Most of the carer voices included in studies such as O'Neill et al. (2022) and Lawn and McMahon (2014) were that of older (but not elderly) white women, caring for children or partners.

Although there were articles across 23 different countries, and there were articles by Cheong Poon et al. (2021) exploring the Vietnamese and Chinese Australian experiences of caring, more generally there was a dearth of peer reviewed Australian based culturally or linguistically diverse perspectives and voice in the literature. None of the articles were identified as being authored from an Aboriginal or Torres Strait Islander perspective.

Five percent of the peer reviewed studies evaluated existing programs, or proposed service provision or 'intervention' frameworks, for example the British COPe-support study evaluating digital psychoeducation and online peer support for the mental health of families and carers who support someone experiencing psychosis (Sin et al. 2022). Eleven percent of peer reviewed studies included methods such as feasibility studies and proposed service models. The majority of the evaluated programs were overseen, or co-run by clinical disciplines such as occupational therapists or social workers. Examples of such studies include Fox et al. (2015, 2023), Hazell et al. (2020) or MacGabhann et al. (2018) who evaluated a trialogue program based in Ireland.

While our research found that 57% of peer reviewed studies utilised a carer only participant cohort, there was also often a reflection in the abstract or discussion section, that noted an absence of family carer voice in research.

An example of this reflection of absence was evident in a paper from 2016, titled “The value of carers in research’ where the author wrote, “...carers rarely feature, and are often invisible even in [service] user-led research” (Kara, 2016, p. 88). Another example can be found in the foundational paper titled, ‘Physical health and mental illness: listening to the voice of carers’ (Happell et al. 2018). The Australian paper which included carer only participants, noted “the voice of carers is particularly minimal, despite policy stipulating carer participation is required for mental health services” (Happell et al. 2018, p.127).

Another paper, this time with a dyad of participant identities (sample of six consumers, and four carers) which was titled ‘Perspectives of service users and carers with lived experience of personality disorder: a qualitative study’, noted that “little is known about carers of those in inpatient forensic settings, yet it has been identified that they may have additional needs when compared to general carers” (Balmer et al. 2022).

Our research found that while carer insight and experience were often reported as a gap in existing knowledge or evidence bases, carers were often recognised in the title of a peer reviewed paper, and located within the abstract, represented in the participant cohort, and sometimes in research findings. However, closer reading of papers found that the actual voice, experiences, wants, or rights of carers, in all their intersectional complexity, capability, despair or fierceness, were often excluded from research conclusions and practice implications. Carers were, arguably, rendered invisible when it came to suggested research impacts.

An example of this omission can be seen in the Happell et al. (2018) paper which included powerful carer quotes in the findings section relating to their own needs, abilities and experiences of trauma, but then concluded the research implications were focused on the utility of carers for service provision and service users. The authors conclude that “Carers are acknowledged as crucial for the delivery of high-quality mental health services. Therefore, they have an important role to play in addressing the poor physical health of people with mental illness. Hearing their views and opinions is essential.” The Balmer et al. (2023) paper similarly noted carers in the study title, included carer participants (albeit a small sample), recognised an existing knowledge gap related to carers, and then focused on the service as the beneficiary of the research impact, “the service would benefit from utilising relational practice models when supporting both carers and service users” (p. 64).

Fifty-six papers, or 37% of peer reviewed literature focus on how services should or could include carers in service delivery. The literature includes studies from Australia, Ireland, United Kingdom, Singapore, Spain, South Africa, Canada, Norway, Malaysia, Sweden, America, Jordan, Turkey and Sudan. Often the studies are related to a particular diagnosis, for instance borderline personality disorder, or psychosis, and/or a particular clinical setting, such as emergency departments in a crisis, or integrated community care. Several of the studies focus on models of care, such as focused dialogue, recovery models, or triangle of care (Jackson et al., 2019; MacGabhann et al., 2021; 2018; Maybery et al., 2021). Other papers explored particular points in the carers’ or service users' engagement with services, such as at admission or discharge. The vast majority of the fifty-six papers were framed from a perspective of ‘what services currently do not offer carers’, and relied on small participant numbers, sometimes in the single or low double digits. Despite the modest numbers involved in some of the individual studies, collectively, the papers reveal several key themes that might be of interest for improving the experiences of carers engaging with mental health services.

Four key themes identified in the literature are: conceptualisation of family carers and the 'carer role' by services and staff; access; models of care or interventions; and organisational policies, guidelines and legislation. Recommendations for service providers based on the peer reviewed papers and carer consultations can be found in the opportunities section of this report.

1. Conceptualisation of family carers by services and staff. Research indicates that mental health staff understanding the nuanced differences and complexities in a care relationship without generalising or pathologising families, carers and supporters, is important for a positive carer experience. Carers are not a homogenous group, and have differences in characteristics, experiences and needs. These cohort variations include differences between carers who identify as a spouse, parent, or friend, as well as long term carers versus new carer, young carer, older carer, or carer of multiple people (Dawson et al.,2017; Lawn & McMahon, 2014)

2. Carers want easy, compassionate, equitable, consistently applied inclusion and access to services, resources, supports and information, both for themselves, their family, and for the person they support.

   Research spoke to the importance of understanding a carer's experiences and needs in "a contextual, storied manner" (Klevan et al., 2016, p. 658). The literature was consistent in suggesting that families, carers and supporters are often not invited to talk, or listened to. The following quote from a Norwegian study participant encapsulates a common carer experience:

"No one has ever asked me before. And so I felt… I'm being taken seriously! And I thought about that as I ran down the stairs this morning to get here, this is the first time that I'm going to tell anyone what I think about all this! At times, this is so tough that I figure I might just as well keep quiet about it… And no one asks." (Klevan et al., 2016, p. 658).

3. Research indicates that the models of care and interventions that carers want are diverse, often dialogically based, innovative and holistic in approach, and consider all the needs of the carer as related to the social determinants of mental health, health and wellbeing (Olasoji et al., 2017; Maybery et al., 2021).

   Examples of the types of interventions carers want access to, include services that are less clinical, less time pressured, and more holistic in approach. The holistic models of care must be integrated to other community services, not just within the mental health sector, but more broadly to services related to the social determinants of health, mental health and well-being, such as housing, employment or family violence (Marqués & Navarro-Pérez, 2019).

   Research indicates that carers might benefit from services which provides psychology, therapeutic music and art options, social work, occupational therapists, and carer peer workers (Berry et al., 2022; Howes et al., 2022; Mercuri et al.,2022). Recommendations across the studies, also suggest providing a triangle of care (consumer, carer and service provider/s), extending the model of recovery beyond the individual consumer into collective or family unit recovery, and a recovery model which pays close attention to the concept of 'hope' (McCathy et al., 2023). Staff recognising the value of short-term approaches, and with all senior staff supporting psychosocial responses and conceptualisations of distress and need, are also suggestions for a better carer experience of services. The visibility of consistent carer support staff is also reported as vital for a better carer experience of service as one carer participant suggests "…building up a relationship is seeing somebody around, seeing that they're approachable, seeing that they're interacting, just being there and talking" (Berry et al., 2022, p. 4).

Research also reports that interventions which provide trauma-informed care and support to carers is recommended, with several papers noting that carers are often traumatised, either by the behaviours of the person in crisis, or by the state service(s) response (Brennan et al., 2016; Hirschi, 2022; Paradiso & Quinlin, 2021;). This finding of caring related trauma was supported in the grey literature as well (Katterl et al.,2023; Tandem Carers, 2023). Services could overcome the inadequacy of service response by providing “timely, respectful, specialist and collaborative crisis responses to carers” (Brennan et al., 2016, p. 452). The same study also states that carers would benefit from a ‘consistent’ experience, one that is characterised by a uniformity in service response. This need for consistency and familiarity or continuity of staff was echoed in other papers, with one research finding that carers need for familiar staff, was possibly linked to the notion of security and an increased chance of inclusion by service providers (Dawson et al, 2017).

A collaborative, transparent, multi-service response is also preferred by carers who are dealing with a mental health crisis, which means that support is coordinated between all services or emergency responders. Carers report that in a crisis, exclusion by service providers only increases their distress and trauma (Brennan et al., 2016). Carers want emotional, psychological and resource support to be provided directly to them when there has been a crisis, during a period of significant change, or ‘acute unwellness’. Carers want to be followed up by professionals, with support related to how they are coping after witnessing a crisis, and they want help linking them with appropriate support, relevant to crisis management (Brennan et al., 2016). It is found that carers are not always aware of what their own rights are, and that there is a role for services or advocacy agencies in providing that information (Daniels, 2023).

Along with the trialogue and open dialogue models, single session consultations, regular family meetings and “simple one session carer involvement” (Kaselionyte et al., 2019) interventions are supported in the research. UK based research provides a model of inclusion that is fairly structured, yet simple (Kaselionyte et al., 2019). Another paper is focused on LGBTQIA+ consumers and supporters, and finds that if inpatient services use the Safewards program, extending this program to include carers, could be beneficial for carers, consumers and service providers (Martin et al., 2019). Standbridge et al. (2013) evaluates a staff training program aimed at improving carer inclusion in assessment processes. This training includes holding a family meeting within seven days of admission, having ward-based carer inclusion ‘champions’ and is teamed with a family liaison service with positive results (Standbridge et al., 2013).

4. Organisational policy, guidelines and legislation which are carer inclusive is vital when related to services consistently and fairly sharing information with carers, about the person they support. Studies show that having consistent national carer partnership standards that organisations must comply with, is also important to carers (Lawn et al., 2020).

At admission to a service, there must be clear and consistently applied guidelines for sharing information with carers, “It’s alright treating the service user, but you’ve got people at home who care for that person, who are going through mental anguish not knowing what is being done to help that person” (Berry et al., 2022, p. 6). Sharing information related to discharge planning was another flashpoint for carers, several studies noted that carers are often relied upon to immediately accommodate service requests when it came time for a consumer to leave a service but are often excluded from discussions or discharge planning. (Maybery et al.,2021)

GREY LITERATURE CHARACTERISTICS

Table 6 outlines the characteristics of the grey literature included in this study. Overall, of the 46 pieces of grey literature, 20 were produced by different Commissions or government departments such as the Queensland Mental Health Commission, the Royal Commission into Victoria's Mental Health System, or the National Mental Health Commission, eight were produced by service providers such as MIND Australia,seven were driven by family carers or family carer workforce, such as the Carer Lived Experience Workforce (CLEW) group, seven others were based in community advocacy groups, such as TANDEM or the Mental Illness Fellowship, two were university products and two were driven by professional bodies such as RANZCP, the Royal Australian and New Zealand College of Psychiatrists.

Examining the table below it is apparent that grey literature is action and change orientated, translating data and insights directly to inform advocacy and reform and lived experience practice. However, much like the peer reviewed literature, grey literature was often written for service providers and for Government instrumentalities and regulatory bodies and for family carer workforce and advocates, but not for family carers in community.

TABLE 6. CHARACTERISTICS OF GREY LITERATURE

SOURCE	TYPES OF LITERATURE	METHODS USED
Practice based and workforce	• Pilot or innovative programs • Practice guidelines • Lived experience discussion papers • Supervision framework	• Consultations • Literature reviews • Secondary data analysis
Advocacy organisations	• Position papers • Reports in response to reform agenda • Submissions for reform and policy submissions	• Co-production • Focus groups • 1-1 interviews • Participatory methods • Surveys
Community service providers	• Guidelines for practice • Organisational readiness • Family inclusive practice	• Engagement & consultation • Staff scoping • Adapting Frameworks outside sector
State and Fed Govt, and MH & Productivity Commissions	• OCP Guidelines • Royal Commissions	• Consultation co-design • Evidentiary approach • Testimonial
Professional bodies and universities	• Position Statements • Health Talks – Stories of carer experience	• Ethnography digital story telling

The methods used fall into three key categories – co-design and participatory approaches, use of secondary data, and consultations through testimonial and formal evidence processes.

Similar to the peer reviewed literature, much of the grey literature was authored by professionals, clinicians, government staff, policy writers or academics, although there were some documents which were co-developed by carers and consumers, or carers, consumers and clinicians, such as the 'Not Before Time' Report (Katterl et al., 2023) which was led by a reference group of consumers and carers, and the Victorian Office of the Chief Psychiatrist's Guide to Working with Families (Victorian State Government, 2018). The Rising Together Report (Rising Together Action Group, 2022) was also notable in that it was primarily authored by the carer workforce, for the carer workforce.

CONSULTATION CHARACTERISTICS

The researchers of this study conducted a focus group of 15 FaRAN family carer researchers and 3 1:1 interview. To protect anonymity identifying demographic specifics are withheld.

Of the 18 family carer contributors, there were people from across four Australian States, and multiple Aboriginal Lands, including Wurundjeri, Turball, Gadigal, Wajarri Yamatji, Mullewa Wadjari and Widi Mob. Most participants were in metro or peri-urban locations, with three people joining the online sessions from regional locations.

Participants ranged from young adults through to older carers, with the majority, but not all, identifying with she/her pronouns. There were participants who supported multiple people, some who supported one person, and a number of participants who identified as both carer and service user.

Several family carer research collaborators were employed in university settings, some were employed in government or mental health service provision, two working in non-government organisations, and a number were independent or community-based family carer advocates or researchers.

CONSULTATION THEMES – INTERVIEWS & FOCUS GROUP

There were three umbrella themes arising from the thematic analysis of the consultative conversations. The themes spoke vividly to the state and nature of contemporary family carer research, as well as the barriers, enablers and facilitators of family carer engagement in research. See Section 2 of this Report for more details on the methods used.

This section explore each theme in greater detail, drawing on direct quotes from the family carer research collaborators to help to illustrate the themes identified. An overview of the themes which arose from the consultations can be found in Table 7.

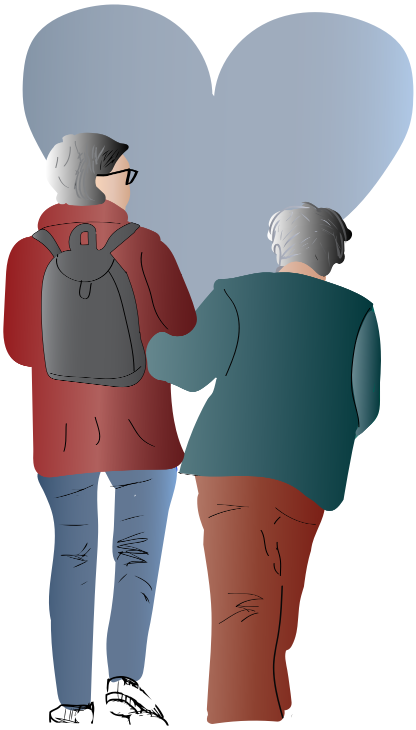


TABLE 7: CONSULTATION THEMES

BARRIERS FOR FAMILIES AND CARERS IN RESEARCH

- Participation in, and opportunities to lead research are often limited by invisibility of family carer researchers - ‘you can’t be what you can’t see’
- Limited educational or vocational pathways for family and carer researchers who want to get into research
- Funding that is driven by the agendas of others; clinical and individualised views of mental health and a lack of funded spaces that are prioritising family and carer research
- Inadequate funding to allow for ‘slow research’ that is needed to accommodate for the intensity or unpredictability of family and carer role
- Research mirroring system positioning of families and carers as unpaid contributors to the sector
- Marginalisation - “Why bother”? Lack of accessible translation and dissemination, means that there is sometimes an unclear return for effort

QUALITY OF FAMILY CARER RESEARCH

- Missing intersectional foci such as research which includes Alcohol or other drugs or forensic mental health.
- Research is missing or ignores the complexity of the carers experience
- Limited research design that doesn’t allow room for inclusion and collaboration with family and carer folk
- Historic lack of opportunities for family carer research leaders
- Absence of research related to, and driven by young carers
- Limited conceptual framing of family and carers, that often overlooks the social determinants of distress

ENABLERS OR FACILITATORS OF FAMILY CARER RESEARCH

- Strong allies across disciplines
- Prioritising upskilling for families and carers who are interested in leading or engaging in research
- Power sharing between academic researchers and those who sit out the academy, or don’t have roles or positions of authority
- Researchers taking time to get to know the family carers they are working with
- Using contemporary language in research
- Providing safety to family carers in the research process
- Research that is aligned with family carer advocacy goals, or which contributes to building advocacy or change
- Building trust between researchers and lived experience collaborators
- Using participatory methodologies, being included throughout the research process

BARRIERS FOR FAMILIES & CARERS IN RESEARCH

Family carer research collaborators raised several sub-themes under the umbrella topic of 'barriers', specifically barriers to participating in research, barriers to accessing useful research they could use in their everyday lives and caring roles, non-representation of their carer experiences, lack of representational definitions of carer, family or supporters, and barriers to leading or co-leading investigations.

Under the sub theme of barriers to participating in research, many family carer collaborators experienced marginalisation, suggesting that it was often unclear why they would nominate to spend their 'precious energy' on participating in someone else's research, particularly given study processes would often feel extractive or transactional, difficult for them to access once completed, and not easily translatable into their own lives. Many felt the research process extractive and transactional.

...why spend my scarce energy and time to engage in research (Collaborator 3).

...what's in it for the people who are, how is this going to come back or is this just going to serve to build, and I don't mean this churlishly, but is this going to serve to build someone's academic career and on the back of difficult experience? (Collaborator 2).

Additionally, carers reflected on elements of research design which acted as a barrier to contributing or participating. Examples included research that did not count partially completed survey responses, research processes that were conducted over a lengthy period, or data collection tools that had too many steps, or a limited way in which data was analysed.

...a lot of the way we do our analysis and the way we even count things so that they meaningfully count if something's incomplete, we very often can't count it. I don't think that provides flexibility for family members who might have to jump, might even be distracted while they're doing something... and therefore it might be incomplete. It means we can't count it and can't use it (Collaborator 10).

I want a tool that enables people to say what they want to say... (Collaborator 15).

Several collaborators reflected on concepts and experiences of shame, stigma, blame and lack of cultural safety as barriers to participation in research. These quotes often related back to family carer's lack of trust in how research will be conducted, framed or disseminated.

I also have observed a great reluctance, perhaps even a fear from family members, particularly in our cultural families, of saying anything that could bring disrepute, shame, embarrassment, anything on the family, their community or the person they care for (Collaborator 10).

There's this fear of looking like it's blaming the person we care for in order to state what our needs or the family system needs might be (Collaborator 15).

Several of the collaborators felt that a narrow and imposed definition of what families and carers might be able to contribute to research projects, meant that carers are not often included in research about other areas or topics considered outside the 'remit' or traditional areas of mental health carer expertise. As one participant said,

I don't think we should let others put us in a box, that says carer research is only about carers (Collaborator 10).

The challenge of carers finding useful, relatable research cut across all three umbrella themes, and the need for using different and multi-pronged communication strategies, to disseminate research to all families and carers, came through consistently in participant discussions.

Is it just going to sit on a shelf somewhere? So, I think we need to improve the communication *around what being a participant or a leader of research (means)...* (Collaborator 3).

In relation to carers leading or co-leading research, collaborators reflected on the barriers for young carers to gain equal education opportunities, and the impact of a competitive research environment once you have gained entry. All of the young carers, and some of the now older carers, spoke of significant barriers to entering educational settings, which led to a lack of formal qualifications, and subsequent exclusion from higher education. This in turn, led to exclusion from being considered for research jobs and lead investigator role in research or policy projects, or from authoring of peer reviewed journals.

In the consultations, young carers discussed how they missed out on formal educational opportunities, which then contributed to the very word 'research' attracting additional negative connotations, as 'a place where carers do not belong'. Although this exclusion from educational opportunities occurs across the lifespan, it was reported as being felt most keenly from young carers:

> *How are carers able to even complete training to then be able to lead research and this is something that I have had to negotiate as a young carer* (Collaborator 4)

> *Caring responsibilities prevent educational opportunities* (Collaborator 11)

...young people, because of caring responsibility missed out...when they hear the word 'research' there's this apprehension (Collaborator 8)

Many carer collaborators also noted that established inequitable social structures contributed to barriers that extended beyond academia, and the mental health sector. Co-researcher and focus group co-facilitator Amaya Alvarez reflected,

> *We know that family carers are often in precarious work situations or have interruptions to their career, so they're not necessarily in the model of gentlemen researchers where they've got the income or the career choices*

Conversations revealed that many of the collaborators did not connect with terms often used in research to describe the caring role. People felt that, while 'carer' was mostly used in research to describe people who support others, not one family carer that it adequately captured their experience or identity, or the experiences of the person they supported. However, the terms operational value, as a label that service providers and government understood, or responded to, was recognised.

> *As a family carer, I don't identify with the term carer. It is often a term that our loved ones, our family members don't particularly like. It implies some sort of control of different power relationship than we actually have in our caring relationships*
> (Collaborator 6)

... I hate the word informal carer, it's just really crappy, it's not dignified at all... (Collaborator 1).

Some collaborators spoke about the definition and descriptor of the 'carer researcher' position, suggesting that there was a general lack of clarity around the skills or experience needed to 'be' a family carer researcher. Collaborators spoke of at least three different 'types' of family carer researchers, characterised in part by employment (or not) in the carer workforce.

> *...my experience as a peer researcher and not an academic researcher, is as a peer practice professional not a carer who's not working in the workforce. So, I think there's a distinction there... we need to be careful that it's not drifting from peer ways of knowing and doing, into academic ways of knowing and doing, which is great, but it's like fitting a round peg into a square hole sometimes...* (Collaborator 9)

There was a strong belief throughout all conversations, that peer reviewed publications were not accessible for family carers, or peer researchers that are based outside the university system. There were a number of examples of inaccessibility shared by collaborators which included: information written in hard-to-understand language or scientific jargon; reports sitting behind prohibitive paywalls or outcomes not being translated into other formats; and impacts beyond peer reviewed academic papers,

...what's missing is how research is communicated back to the community
(Collaborator 3)

there are other forms of material that you generate out of a piece of research that's not just peer review research. So, it may be position statements, it might be policy documents... (Collaborator 10).

I think the reason the research is being overlooked is because most of it is behind paywalls, which most people, most family members can't access (Collaborator 2)

Collaborators often spoke about 'closing the loop' on research, which meant letting carer participants know what will become of the research they contributed to, how it impacted family carers more broadly, and producing research that is widely disseminated and easily translatable.

...completing the circle of research and then advocacy and then policy change or whatever or legislative change or even just program change whatever it might be that you're seeking to improve...(Collaborator 2)

Many carer collaborators felt that adequate, equally applied funding was not readily available for family carer-led research. One collaborator captured this sentiment by relaying

I think there is a gap in relation to family carers being able to be funded to do the research that they lead (Collaborator 8)

Collaborators also noted that funding was inadequate for what we labelled “slow research”, which is a pace of investigation which is sometimes necessary for family carers who may be traumatised, unwell themselves or juggling the commitments of caring for others;

*...to be able to do this research work, it takes time It takes immersion. You can't just do it for a couple of hours once a week or something like that. It takes time to sit there, look at papers, let things sink in...so there there's the knowledge gap, gap in knowledge about the system, but also needing to feed themselves (*Collaborator 8)

There were also concerns raised about the impact of small, pilot or seed funding grants on the wellbeing of the carer research community itself;

...because there's such scarcity, that there is a little bit of competitiveness which is I think, probably quite common, and I don't know this for certain, but I assume it's quite common in academia, but it's not something that I would like to see in the family carer space where that is not the way we operate. It's not kind, and it's not compassionate and I think that's quite a challenge and that's quite a challenge then also to try to do things collaboratively or co-produce or co-design anything even, because the amount of money is so small (Collaborator 15)

For many carers, applying for project funding was still an inaccessible and unequal playing field, with collaborators prosecuting who was often tasked with creating funding processes and criteria:

...the criteria will be put together by well-off, middle-class, upper-class men, white privileged males, nothing against any men here, please, but like, last century (Collaborator 10).

Carers raised that funding was often inadequate to ensure projects could be led by individual carers trying to build research capacity or develop new skill sets, or who are juggling competing commitments;

...the importance of resourcing and funding, that when someone’s trying **to build and** *develop their capability and do it fast, that’s got to take a bit more time, because they’re learning compared to someone who might be able to, who’s got that knowledge, got that ability and knock it over in 1/4 of the time* (Collaborator 11).

QUALITY OF FAMILY & CARER RESEARCH

This theme includes gaps in representation and positioning of carer identities, missing experiences and insights, as well as limitations in the conceptualisation of carers within contemporary evidence.

Most of the family carer research collaborators reported that they noticed a lack of intersectional perspectives or experiences captured in current peer reviewed research. While there was some literature on dual disabilities, namely physical and psychosocial disability, many of the carers with experience of supporting someone who has forensic or correctional intersection, as well as Alcohol and Other Drug (AOD) experiences, noted a scarcity of relevant or relatable literature. Participants expanded on why diversity of representation in this research mattered:

...there's lots of research on family where it's disability or whatnot, but not with that intersectionality (of forensics) and the impact on families of actually managing that and managing bail systems, managing perception, stigma in terms of what that is for them... (Collaborator 2)

...is the dearth of research for families when there's a intersectionality of mental health, forensic, alcohol and other drugs (Collaborator 3)

Collaborators felt that research rarely explored the intersecting experiences of being both a carer and consumer, with many arguing that they sometimes felt like they were forced to choose a singular identity. One person articulated that they were interested in research that focused on collective experiences which were inclusive of both consumers and carers:

...what families are, we're not consumers and carers, we're people and families and families of choice as well (Collaborator 15).

Most carers reflected that the focus of research papers, often ignored the complexity of the carer experience, and that often-cited research, did not adequately highlight or prioritise the complexity or full range of the carer lived or living realities. Examples of the missing nuances discussed by collaborators included, experiences of carer suicidality, carer trauma, impact of long-term care giving, and other "meaty topics":

I think that means in our research, there's a holding back from being able to do the robust in-depth look at examples such as suicidality and carers, other kinds of the health and wellbeing long term impacts, not just the immediate short term needs around say, respite and things like that (Collaborator 10).

I also feel that what has dropped off the radar substantially in the last 20 years has been those carers who themselves are consumers...and it's like you're siloed in these lanes rather than seen as a whole person in the whole of who you might be and whatever might be going on for you, which may or may not have anything to do with the caring responsibilities (Collaborator 10).

The research on the impact of trauma and health outcomes for our families, especially when there's long-term advocacy and managing system failures over long periods of time... (Collaborator 3).

I think it's a challenge in the consumer-led research space too, rallying around the word consumer, not everyone relates to that, but it's definitely a challenge for family carers (Collaborator 6).

...it seems to be the research is still focused on the journey of a person with consumer lived experience (Collaborator 10).

Collaborators also felt that a recognition or demonstrated understanding of the unique culture of each family unit, was also underrepresented within contemporary evidence:

So I think there's hardly any research just on the experience of the family in its own right, with *its own idiosyncrasies, nuances and all of that* (Collaborator 3).

Most family carer collaborators said that they felt invisible within research design, processes and research translation

It was thought that competitive and individualistic research structures contributed to carer marginalisation, in a culture of competition and hyper-individualism, which is reflected in grant processes that require a singular chief investigator, or universities whose pathways to promotion meant individual academics are pushed to claim authorship ahead of their lived experience counterparts, or institutions claiming lived experience credentials where there are none.

Family carer research collaborators also reported uneven attention given across carer topics, cohorts or research areas. The content areas which were nominated for missing focus included children of parents with mental illness, carer workforce and young carers specifically in the age range between 18 and 30 years of age.

There is a lack of good, robust Australian research about us, about carer leadership, about carer positions, and in specific populations or needs or any of that in the workforce… (Collaborator 10).

Other collaborators spoke to researched areas that were the focus of individual researcher allies;

I know that there is quite a lot of research happening in the children of parents with mental illness (Collaborator 5).

It was also suggested that the focus of 'lived experience research' as an umbrella term was heavily weighted towards consumer research, both in participation and content focus.

I've been concerned about different organisations purporting to be lived experience led and then putting out funding grants that don't support lived experience leadership, for instance that have to have someone with a PhD leading the research and then promote the individual, that this individual has been successful in getting this grant rather than there's a whole collaborative (Collaborator 15).

Young family carer research collaborators spoke about the impact of a lack of research on their own experiences of transition from being a young carer to someone who is seen by services as an adult carer. There was a sense that research about young carers, and age transitioning carers, was very much in its infancy, and that a lack of evidence, negatively impacted the way services then engaged or supported them,

Young carers are an area that I don't see a lot of work emerging from (Collaborator 16).

Those between 20, or after 18, and 30, are left behind or forgotten from the focus of research (Collaborator 7).

...there weren't a lot of papers on that topic and that actually a lot of organisations weren't thinking about that transition to adulthood, which I thought was really interesting because it's true, I've experienced that as a carer myself that transition isn't there. I suppose a lot of organisations are still at that starting point of even being like, hey, we're an organisation for carers and even talking to adult carers, some of them are like I've never gotten support, and now I finally have and they're a lot older now in their life. They could have got that support earlier. I think that's what I'm seeing in the research, it is still in that baby little infant stage (Collaborator 16).

Many of the collaborators felt that the conceptual framing of family carer research impacted the usability for them, as it was deeply rooted in a bio-medical paradigm, but they also recognised that it is often the only framing that carers are aware of as they start the carer journey. This medicalised framing was picked up in the way that research was often aimed at improving programs or service delivery, rather than focusing on the carer, their perspectives, their needs or curiosities.

But the focus is still on improving systems etc for the person that's actually accessing, so there's not a lot of research about the family carer lived experience in its own merit (Collaborator 3).

> *I think there's quite a substantial body of family carer research, but it's not always written by, controlled by, through the lens of family carers themselves, with carer experience that is hidden because it's not safe to take on multiple identities.* (Collaborator 6).

ENABLERS OR FACILITATORS OF FAMILY & CARER RESEARCH

Family carer collaborators nominated several enablers to engaging in research. These included the importance of allies in research, equity in professional relationships, a commitment to funding and prioritising upskilling for family carers who are interested in leading or engaging in research, as well as access to literature and conference attendance.

I think there are some quite strong allies out there who may not necessarily be family carers, but they recognise the need for this research (Collaborator 8).

The act of power sharing was also mentioned as an enabler for carer engagement in research activities. One participant suggested that;

Where imbalances and power and things like that are called out and acknowledged from the very start, and that there's not just reciprocity, but equity in the relationship (Collaborator 10).

Having networks or community of practices was recognised as a vital enabler, many participants noted that within the last five years in the State of Victoria particularly, mental health family carer perspective researchers and research leaders, were increasing in visibility and impact, due to the development of networks like FaCRAN and FaCWRN.

It's been very exciting in the last five or six years to see more family carer leadership voice (Collaborator 6).

Coinciding with the development of FaCRAN, and in NSW the Carers Knowledge Exchange, collaborators spoke to an increase in national, sector wide grant opportunities and funding for carer led research projects, suggesting that there had been a notable increase over the last 3 – 5 years for funded research. Participants reported:

*...there's been a significant spike in interest from researchers' funders about carer focused projects...we've certainly noticed around partnership and success for grants that there definitely seems to be more attention at that level on research (*Collaborator 12).

Individual renumeration of research carer participants was also discussed, with consensus that paying family carers for participation in research was a positive commitment for the participant, and the investigation process and outcome more broadly;

...funding the carers or the carer group directly seemed to help a great deal (Collaborator 6).

Collaborators were also able to clearly identify several characteristics of 'good research' process and outcome', these included researchers taking time to get to know carers, being respectful, not extractive, prioritising engagement and reciprocity, using contemporary language, providing safety and support for participants, being trauma informed, building in participant upskilling into the research process, and allowing time and space to focus on the tasks.

..in terms of the relational rather than that transactional approach, and where I have been involved most effectively is when the power imbalances were explicitly surfaced and addressed, and also where there was a very clear reciprocity (Collaborator 2).

I think good research would be that the people who are conducting the research are on board with contemporary practice language (Collaborator 3).

Having family carer researchers leading the research meant that carer participants felt less compelled to share difficult details of their lived or living experience, a process that can be distressing for them. One young family carer research collaborator shared;

I like to get to know the person doing the research a little bit because I feel like trust is so important. Like you're divulging some of your lived experience, what you're going through, and I think trust can even just be like someone on the team having that experience. So I know, OK, if I'm going to talk about something I don't have to go into it too deep because that person there is going to know, 'yep, I get it' (Collaborator 16).

Using participatory methodology and including carers in the pre-design phase was a thread through much of the participants reflections on 'good' or positive experiences with research.

If they (carers) are actually identifying the subject matter or the need, and the engagement is done safely and in an effective way (Collaborator 2).

Additionally, collaborators felt that researchers identifying as a carer, while a positive attribute, sometimes wasn't enough to ensure 'good research', with a preference shown for carers who have used their experience professionally in a way that demonstrated an expertise.

...what makes good family carer research is people who have experience of using their experience as a family member or carer, not necessarily in research, because those skills can be taught, but those people have had their experience of using their lived experience as a worker, are leading the project involved in the project in a in a really deep way. They feel confident and empowered to halt the process if things are not going in a way that is aligned with a family carer perspective (Collaborator 15).

Family carer researchers want to be involved in projects that will have direct impact for carers. For family carers who are not involved in producing research, they want new knowledge or information that they can identify with, and that has utility for their lives, and the lives of the people they support. This sentiment is captured by one of the collaborators;

The best research for me has been where I've read the findings and I've gone, 'this helps me understand what happened. This helps me. I can see something

Arksey and O'Malley's (2005) scoping method calls for the use of an analytic framing of the scoped literature in order to present a logical, cogent narrative of the data. Holding critical consciousness theory in our minds, as family carer researchers, it was vital to apply a critical lens or framing, with a particular focus on power and oppression, to the charted data and consultations (Allen, 2023). It is clear from the quantity of contemporary publication that research related to family carers is being produced within Australia and globally. It is equally clear that in the State of Victoria, through the RCVMHS process, researcher allies and researchers with lived experience of care giving, produced compelling evidence of carer contributions and experience, as well as how the mental health system failed carers.

Those existing dominant models of how we understand and respond to mental distress and care giving, as well as associated structural power dynamics, have arguably conspired to cast a shadow of doubt over how representational family and carer research is, and whether the research produced is always accessible for all families, carers or supporters.

This family carer-led Report signposts a way forward to a future where contemporary family and carer research will become more representative of all family carers, more equitably accessible and useful, but only if; carers are central to, and visibly lead or co-lead all aspects of research and knowledge development, strategy and dissemination. If, participatory methods are used, and research projects prioritise the rights, needs, curiosities or wants of family carers above that of service providers, economists or policy makers, particularly when it comes to imagining the real-life implications of the research.

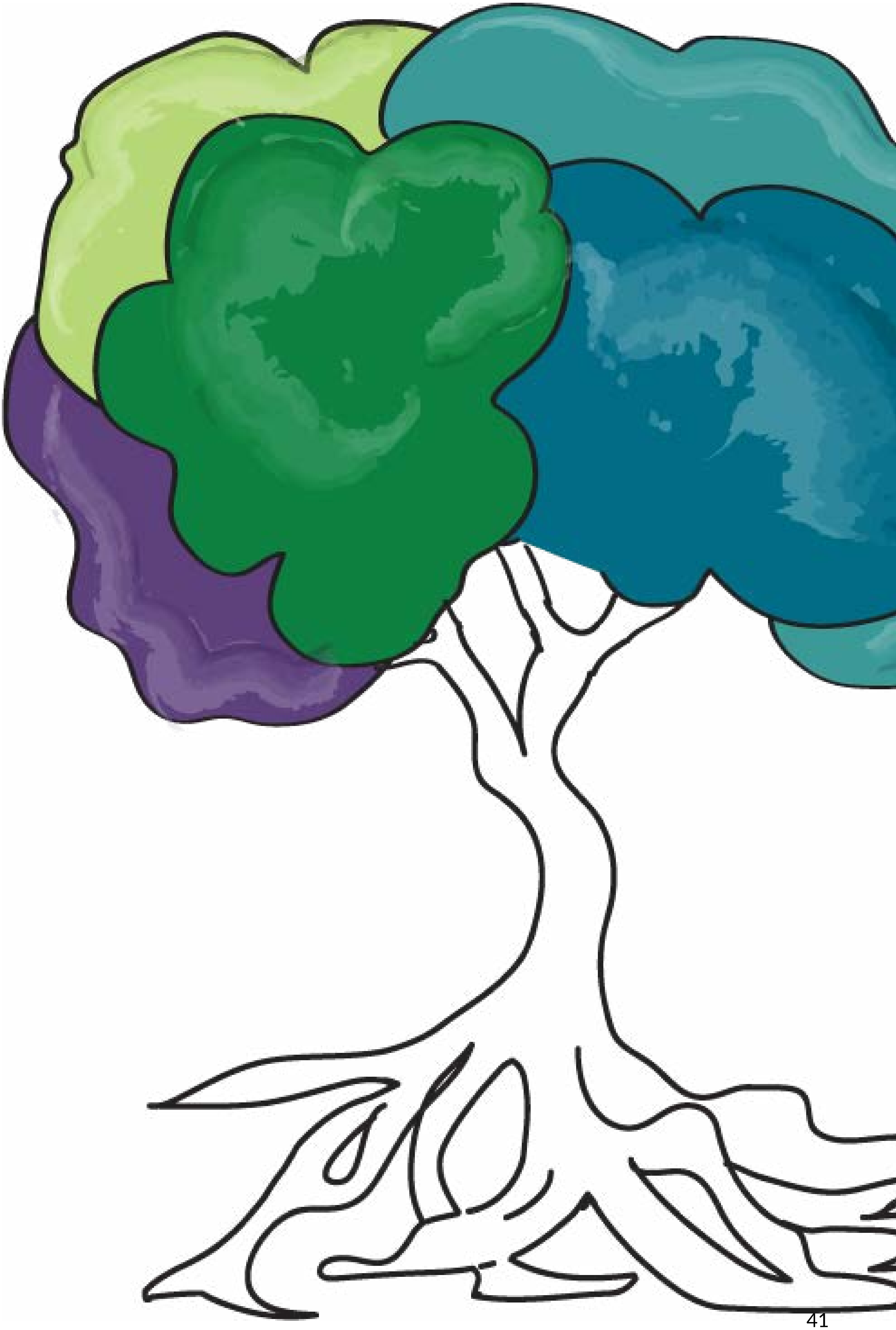
LACK OF DIVERSE PERSPECTIVES OR NUANCED REPRESENTATION

Family carer research collaborators were clear that the complexity and nuance of care giving experiences were largely absent from the carer research they were familiar with. Forensic, AOD, experiences of poverty, precarious housing or LGBTQIA+ intersections with care giving were notably often missing from contemporary literature, which is problematic given what is known about the connection between social determinants, caregiving and carer health and wellbeing (WHO, 2022; Savela et al. 2021).

There are number of reasons why more nuanced perspectives were often, but not always, absent in the peer reviewed material. Hermeneutical injustice caused by systemic or institutional dynamics will be discussed in a further section, but collaborators also suggested that the more controversial or critical topics, were not given voice through fear of undermining or offending the people carers support, or for fear of having carer insights weaponised by service providers against both people with lived experience of mental distress, and those who support them.

While there were two peer reviewed papers that explored some of the moral and ethical challenges for carers navigating coercive treatment of the consumer (Norvoll., 2018; Rugkåsa & Canvin, 2017), and ten papers that explored experiences of stigma (although sometimes findings were related back to implications for a service, treatment or discipline), the more mundane, confounding, or shame inducing aspects of caring were sometimes found to be missing as the focus of peer reviewed literature. Carers would need to access grey literature, community organisations, peak bodies or research or support networks in order to find such experiences spoken of (Healthtalk, 2024; Lambert, 2022; Katteryl et al. 2023).

Like others have noted, there was a lack of Australian based, culturally and linguistically diverse (CALD) carer perspective research



(Poon & Lee, 2019), and similarly to other marginalised perspectives, CALD representation might be found more readily outside peer reviewed spaces, see Victorian Transcultural Mental Health (2014) ‘Our voices: Stories from carers from refugee and migrant backgrounds’, for a creative examples of how CALD carer experiences can be captured. A lack of culturally focused carer evidence risks contributing to a further invisibalisation of the caring experience for culturally and linguistically diverse family and supporters.

There was a lack of Australian based, culturally and linguistically diverse (CALD) carer perspective research (Poon & Lee, 2019), and similarly to other marginalised perspectives, CALD representation might be found more readily outside peer reviewed spaces, see Victorian Transcultural Mental Health (2014) ‘Our voices: Stories from carers from refugee and migrant backgrounds’, for a creative examples of how CALD carer experiences can be captured. Within the scoped literature, there was only one article that explored the rural Australian carer experience (Dawson et al. 2017) and while it provided excellent insights, the South Australian based sample size of 5 older carers was small and didn’t include remote perspectives, which may differ from regional or remote insights and needs.

A lack of culturally focused and geographically diverse carer evidence risks contributing to a further invisibalisation of caring experience for culturally and linguistically diverse family and supporters.

The idea that carer identity, or ‘form and function’, is often constructed by ‘others’ (Armitage , 2014) was reinforced throughout the scoped literature and consultations. As one participant reflected “For me, it [the label carer] wasn't self-chosen for me, it was something that a colleague described to me as being a carer and I hadn't really seen myself in that way...”

This construction of carer identity and role by others, was extended to a positioning of family carers within research as a ‘data set’. This was picked up in an article by Lawn and McMahon, who note studies “tend to discuss carers’ experiences through an “othering” lens, as research objects (Krumer-Nevo & Sidi, 2012) rather than their story being told from their perspective, or by researchers who are mental health carers.” (Lawn & McMahon, 2014).

On a macro level, government policy responses regularly highlight the economic contribution that carers make (Diminic et al.,2017). Economic modelling by Deloitte revealed that unpaid carers make vast social and economic contributions to Australia each year, noting carers provided 2.2 billion hours of informal care each year, with the cost of replacing this care valued at $77.9 billion. This care provision is only likely to have increased in light of the recent pandemic. However, it is not the figures themselves which our carer collaborators take exception to, the figure feels like a fair estimation of the amount of unpaid labour that carers provide, rather the continued tying of care provision to cost saving, or commodifying care, is the affront.

This structural commitment to ensure carers remain as unpaid carer providers, is evidenced more recently in the Commonwealth Government's ‘Draft National Strategy for the Care and Support Economy Strategy’, which listed in the Goal 1 objectives., “the contribution of informal carers is valued, and they are supported to sustain their caring roles” (Australian Government, 2024, p. 3).

Family or carers who support someone experiencing distress, are, arguably often positioned by clinical services as sources of information or ‘collateral’, or tools by which we can make services or clinical disciplines deliver ‘gold standard’ or ‘best practice’ programs. We saw this positioning reflected in the high number of papers that highlighted the contribution that carers make to evaluating services, uplifting clinical or community programs, or in showcasing how well certain disciplines can be allies to those of us with lived and living experience. This organisational and service ‘extractive’ positioning, mirrors how government structures view carers as resources to harness or exploit and highlights why it becomes deeply painful and problematic that family carer research is often led by others.

HERMENEUTICAL INJUSTICE

Although there are some notable outliers, contemporary ‘mental health’ peer reviewed literature is dominated by operationalised and homogenised definitions of ‘mental health carers'. As one of our family carer research collaborators said, "So I think there's hardly any research just on the experience of the family in its own right, with its own idiosyncrasies, nuances and all of that".

A biomedical or bureaucratised lens in research may mean that family carers, kin or supporters are defined narrowly by others, thereby preventing them from claiming more complex, contradictory or nuanced identities or experiences. As already argued, hermeneutical injustice may be being perpetuated, and carers positioned as tireless, selfless (and willing) care givers by design, in order to continue saving governments billions of dollars in unpaid care provision and effectively propping up a system which is often absent or brutal in its presence (Issacs et al. 2024; Katterl et al. 2023).

For family carers, hermeneutical injustice occurs through institutional or structural actions, this silencing occurs every time carers are denied expression of their multiple identities through flawed research design, or limited data collection tools. Our family carer research collaborators spoke clearly to some of those research design barriers, such as not being able to relay their fulsome experiences, or tick both carer and consumer on surveys for example. The collaborators also noted in research process, carers are frequently discouraged to use their unique voices to express experiences, to explore ‘meaty topics’ such as carer suicidality, or the difficulties of navigating supporting across multiple systems like alcohol and other drugs, forensic and mental health.

A culture that continues to cultivate hermeneutical attitudes, serves to close minds to alternate expressions or interpretations beyond the dominant discourse (Medina, 2019) - which in turn sustains the marginalisation of family carers, with our most underrepresented support givers, continuing to be amongst those who suffer the most harm as a consequence of not having their experiences addressed through a broad evidence base.

IS THE ‘RIGHT EVIDENCE’ BEING PRODUCED?

Not necessarily. Some of the Australian carer led, co-created evidence has been incredibly powerful in highlighting unmet needs of carers, examples of such research include, Issacs et al. 2024; Walters & Petrakis, 2022; Maybery 2021 & 2022; Banfield et al. 2018; Brennan et al. 2016; Lawn 2014 & 2020 & Mercuri, 2021. However, while the considerable evidence on the need for increased meaningful inclusion in service provision and planning is potentially useful for service providers and carers, there is still a significant lack of evidence that explores the experiences of families and carers who sit outside a ‘mental health system’ either deliberately, or due to accessibility barriers. We know that this excluded population is both considerable and potentially underestimated in size, with certain populations like young carers (and people experiencing distress) disproportionately marginalised (ACT Government, 2022; Mental Health Carers NSW, 2020). The ‘service centric’ focus of much existing evidence speaks both to the pervasion of a medicalised model of understanding and responding to psychological distress, and an under valuing of lived and living expertise and knowledge.

Indigenous wisdoms are also underrepresented in the current peer reviewed evidence, although this doesn't necessarily mean that the evidence is not being produced, or that there are not peer reviewed published authors who identify as First Nations. This underrepresentation might be due to a number of limiting factors within our own study (i.e. all non-Indigenous project team, and search terms that do not necessarily reflect Indigenous knowledge), or could be due to reasons that sit more broadly at a societal level, including but not limited to the colonisation of knowledge systems and structures, associated de-valuing of First Nations expertise, and the notion that First Nations evidence may in fact be held in other less hostile spaces, a d that for First Nation folks, the label of a singular carer is highly problematic in richly articulated familial and kinship circles of caring (Better Health Channel, 2015).

Arguably, preferred methodologies such as survey, often added less nuanced or impactful insights for family carers, than exploratory or participatory methods. This desire to capture the complexity of family carer experience is reflected across the three consultation themes, but it was the limitations of the methods employed in research, that many collaborators picked up on, “I want a tool that enables people to say what they want to say...”

As well as limitations in the conceptual framing of the carer experience, blunt data collection tools, having carer identity and role defined by others, collaborators and literature alike pointed to the inconsistent and contested description of ‘carer’, with one recent literature review noting a “lack of clarity around terminology persists” (Browness et al. 2023).

Is the existing evidence being heard? Not necessarily. Despite evidence being produced across the last decade, from around the globe, unequivocally reporting that thoughtful inclusion of families and carers in service planning and provision can be done and will produce better outcomes for service users and their families or carers, this inclusion often still fails to occur (Dawson et al. 2017;RCVMHS, 2021; Mayberry et al. 2021; Fox, 2022).

Australian family carer advocates, peer workforce and researchers, often hear that there is ‘no family carer related research’, when in this investigation alone, there were more than eight meta literature reviews, indicating that there are, in fact, significant amounts of evidence related to families and carers. Perhaps, though, the belief that there is no ‘family and carer’ research is related more to a flawed framing and definition of carers within existing studies, a lack of visibility of the carers who are already producing research (researchers who have carer lived experience), as well as few family carer researcher-led (Carers in dedicated research positions who demonstrably use their expertise within the research project) projects - rather than the complete absence of the work itself.

CARER RESEARCHERS MUST LEAD RESEARCH AND PUBLICATIONS

With increased value placed on surfacing lived experience within research, it is time to move beyond viewing family carers solely as sources of data, and ensure greater visibility by including carers, ethically and purposefully in all aspects of research, including authorship. It must be acknowledged that there are structural barriers to carers being included in publication, such as an imperative for academics to be ‘first’ author because universities use ‘first author’, or peer reviewed publication as a metric for academic promotion or merit (Rawat & Meena, 2014). Other barriers include discrimination or stigma related to being a family carer (Olasoji, 2016), not wanting to inadvertently identify the person, or people you support, as well as the restrictive national or institutional guidelines around author attribution. Arguably, the lack of visibility of carers in research design (i.e. author A used their experience of care giving to inform the research aims) and authorship, feeds the trope that there are no family carer researchers.

In the 2019 paper on carer perspectives of secure long stay forensic care, the authors note in the discussion section that “a strength of this research was therefore the involvement of a carer at the planning, data collection, and analysis stage, in which it was recognized that no standpoint had an ontologically privileged position but an equally valid perspective” (Sampson et al. 2019), however the reader cannot assume that any of the authors are family carers researchers unless it is evident within the paper.

There are, however, several examples of purposefully including carer researchers in the research design, as well as in authorship. Purposeful carer inclusion was often found in the methodology section of a paper, or through the discussion, and can be seen in the study by Wyder et al. 2018, who wrote “to ensure that the voices of the families was represented at the analysis stage, a carer consultant (KM) was part of the research team.” Lawn and McMahon wrote in their 2014 paper on the importance of relationship in understanding the experiences of spouse mental health, "Becoming a spousal carer 10 years ago prompted her [the first author] to ask more questions: Is the experience of being a spousal carer different from caring for an adult child with mental illness? If so, what is different? Do spouse carers share experiences similar to each other's? The second author—a person with mental illness, a carer, and a national advocate for consumers and carers—posed similar questions".

Another example of how carer identity can be visibilised within research, specifically participatory research, comes from a study in the State of Victoria. "A co-operative inquiry was undertaken with four family carer lived experience advisers and four project officers, who are staff of the peak body and all with lived experience of supporting people with mental health challenges..." (Walters et al. 2023).

Family carer researchers, who are in dedicated or designated carer research roles, need to be recognised as part of a growing carer workforce. The burden, or impact of carers leading research in the current research environment was raised by a number of collaborators and could be a considered an additional contributing factor for small numbers of carer-led research. Traditional research academies, can, at times, be hostile environments for lived experience researchers, with characterised by experiences of discrimination and stigma, which led to further silencing through acts of microaggression (Baidawi et al. 2023; Medina et al. 2019; Hawke et al. 2021). There is an opportunity for the Victorian Collaborative Centre for Mental Health and Wellbeing to learn from the Rising Together project that identified large workloads, isolation and marginalisation, and high levels of unpaid work amongst family carer workers as some of the challenges that contribute to high turnover and levels of carer workforce distress (Rising Together, 2022).

Concerns around co-option of family carer work by researchers less qualified by lived expertise, sometimes means that carers may put their own wellbeing on the line to deliver large projects with limited funding, as one of the collaborators noted,

...we're worried about, who else will do it if we don't do it ourselves...when we try to do too much with too little, what ends up happening is the people that are working on those projects end up getting really burnt. Because for me, my expectations don't meet the reality. I can't do what I want to do and the way that I want to do it, and so then I end up having to accept like a substandard result or getting frustrated that things are being pushed forward at a pace to meet a deadline, rather than thinking about quality (Collaborator 16).

Family carer research collaborators offer the solution of investigating relationally, inclusively, gently and ethically because "...if it's not working for all of us, it's not working.

We can't change the world, but what we can do is interact with each other and the ways that we would like to see that happen and hold space for each other and then move forward trying to find a way that seeks to do no harm and do the best good.

(Collaborator 16)

There are opportunities for growth in every reflection on the barriers, challenges and limitations of family carer research. The collaborators are cognisant that there are exciting opportunities as well as environmental constraints. The insights and reflections that have been identified by family carers in this study need to be prioritised for resourcing, both in order to deliver more targeted support to Victorian families and carers, but also because in prioritising the relational, the diverse, and the collective, we may contribute to shifting some of the entrenched mental models, and 'ways of doing' that underpin current mental health sector responses in Victoria, and Australia more broadly.

LIMITATIONS

- While care has been taken to include studies that prioritized the perspectives of carers, it is possible that papers may have been overlooked.
- The English language was used as a filter in the scoped literature, which may exclude the perspectives of people whose main language is not English.
- Aboriginal and Torres Strait Island perspectives remain underrepresented.

OPPORTUNITIES FOR THE VICTORIAN COLLABORATIVE CENTRE FOR MENTAL HEALTH & WELLBEING

Priority opportunities start with specific opportunities or recommendations related to service delivery, and then fall into Initially investing in communities (or 'ponds') that nurture, mentor and grow family carer research capacity, as well as prioritising funding for research, knowledge and practice translation for particularly underrepresented carer cohorts. Resourcing 'ways of engaging' which are genuinely innovative, participatory in nature, and focused on diverse and representative family carer experiences.

OPPORTUNITIES & RECOMMENDATIONS RELATED TO CARER FOCUSED & INCLUSIVE MENTAL HEALTH SERVICES

CONCERNS OR BARRIERS TO CARER FOCUSED & INCLUSIVE SERVICES	Suggested strategies for service
Interactions between clinicians and carers are not always respectful or helpful for carers (McCann & Bamberg, 2016; Kaselionyte et al., 2019). Carers need more resources and psychosocial spiritual support, sometimes for their own needs, but also in relation to the person they support. Lack of service support for carers supporting someone using antipsychotic medications (Morrison & Stomski, 2017, 2018) as well as lack of support, advice or advocacy for carers supporting someone who is detained for involuntary treatment (Rugkåsa & Canvin, 2017).	Ensure clear, co-designed policies related to access, engagement and support for family, carers and supporters. Consider the co-designed 'Working with Families Training' from Tandem. Also follow the Victorian Office of the Chief Psychiatrist (OCP) 'Working Together with Families' Guidelines (2018). The OCP guideline has a useful self-audit tool for mental health organisations. Provide carer peer support and advocacy services (Mercuri et al., 2022, Rising Together, 2022). Offer support which is dialogically based. Provide emergency and respite funding for families and carers, on top of what is currently available through the Carer Support Fund (CSF).
Carers sometimes experience caring-related trauma (Tandem Carers, 2023)	Ensure trauma informed care is available for carers.
Carers are sometimes excluded from information as staff are unsure of the legislation on sharing information.	Provide training for staff on interpreting confidentiality and privacy policies and legislation
Young carers are often not recognised and included by service providers (Hameed et al.,2023).	Identify and include young carers in treatment plans. Ensure staff are aware of and connected with the Satellite Foundation.

CONCERNS OR BARRIERS TO CARER FOCUSED & INCLUSIVE SERVICES	Suggested strategies for service
Carers (and services) are sometimes unclear about the rights of family, carers and supporters.	Invest in research, legislation and proactive education and advocacy on carer rights.
Recovery models must include recovery for family carers (Fox J, 2022; Fox et al., 2015; Hungerford & Richardson, 2013; Israel et al. 2023, Poon et al., 2018).	Facilitate consensus amongst staff on including families and relationality in the concept of recovery. Consider co-developed training on family and carer recovery.
Measurement tools do not always capture what is useful for carer related service improvement (Maybery et al., 2021, 2022).	Use measurement instruments that are developed by carers.
Lack of understanding from services on care giving within the context of collectivist cultures (Magan et al., 2022). Hyper-individualised mental health service responses can alienate and harm family, carers, supporters and communities.	Build practices and responses that are culturally inclusive and safe. Consider a transnational collectivist approach to service delivery particularly for migrant and refugee populations (Magan et al., 2022). Extend the model of recovery to include relational recovery, family unit and collective recovery.
Discrimination and stigma may be internalised with power dynamics not always being overt or easily identified by carers (McNeil, 2013). The reason behind the experienced stigma may be multilayered (Mignone et al., 2018; Sawrikar & Muir, 2018).	Foster a culture of resistance by cultivating a critical awareness for carers of dominant discriminatory attitudes and practices. This culture might also feed into a co-designed program of carer rights awareness raising, advocacy and education or training.

PRIORITISE AREAS, DEVELOP & RESOURCE

TIMELINES	ACTION
Immediate-ongoing	• Prioritise the funding of a First nations-led research framework for and implementation of research projects exploring Indigenous frameworks and collective community responses to distress, relating to family carer context. Consider how learning might be respectfully supported and shared across all current research practice and responses.
Immediate-ongoing	• Develop, foster and fund young carers research group(s), and ensure that there is a "baked-in mentoring" that occurs within all research projects
Immediate-ongoing	• Fund more inclusive pathways for families and carers co-lead research. This might include micro-credentialling (which needs to be developed), funding, scholarships, or research stipends that financially support carers back into study.
Immediate-ongoing	• Build family carer researcher allies across other organisations that can partner with, co-plan and co-lead family carer research opportunities.
Immediate-ongoing	• Ensure carers co-lead VCCMHW research that is both related to care giving, as well as not directly related to their identified role.
Immediate	• Prioritise funding of research that investigates the unique experiences, needs, as well as innovative support solutions for regional, rural and remote Australian mental health carers
Immediate	• Prioritise funding of research that is lead or co-lead by CALD carers.
Immediate-ongoing	• Support and resource small, deep ponds of family carer research, rooted in community, connected to people, place and location. ...create pockets and work really deeply, relationally and have some really good stuff happen and then encourage others, or others might be motivated to do something different through seeing what's happening in that space.

WAYS TO ENGAGE

TIMELINES	ACTION
Immediate-ongoing	• Fund and prioritise carer projects that allow for 'slow research' ensuring generous or expansive timelines.
Immediate	• Fund lived experience (carers and consumers) researchers to co-produce new mechanisms for procuring their services - focusing on ensuring collaboration not competition.
Immediate	• Lead system change by using inclusive or transformative definitions of expertise, knowledge and research in the VCCMHW research strategy, clearing house and other research functions.
Immediate-ongoing	• Prioritise research that focuses on care giving, using a critical framing that includes all the social determinants of wellbeing and despair, rather than a purely biomedical framing. Poverty, genocide and war, refugee and immigration, gender and sexuality, alcohol and other drugs, and correctional or justice need to be prioritised as intersectional experiences.
Immediate-ongoing	• Prioritise funding projects that use participatory frameworks, orientation or methodologies. ***It would be excellent to have more co-produced research, more lived experience led research.***
Mid-term	• Prioritise (fund, showcase and embed learnings into VCCMHW research & service delivery) projects that promote greater understanding of how power operates and impacts family carers, and carer workforce within mental health and research eco-systems, as well as reform spaces. ***How do you address power? How do you respond when what one group wants might negatively impact another group and how do you hold that in the group when there are different positions which might be painful for some people to hear?***

WAYS TO TRANSLATE & DISSEMINATE

TIMELINES	ACTION
Immediate	• Ensure family carer researcher perspectives are central to any VCCMHW translational and dissemination research strategies or functions.
Immediate	• Utilise the co-designed 'good research' guidelines for researchers and carer participants, which include information on keeping carer participants 'in the loop' with research impact (see Appendix 4)
Immediate-ongoing	• Fund carer and carer researchers to develop mechanisms and clear guidelines that ensure carer author attribution.
Immediate-mid term	• Partner with existing metropolitan and rural, regional and remote family carer research ponds to collaborate on research, knowledge and practice translation and dissemination.
Immediate–mid-term	• Host or co-host research seminars, conferences, or forums which plat-form contemporary carer-led research.
Mid-long term	• Consider building VCCMHW translation functions similar to Yale University's technology transfer hubs, enabling innovative family carers ideas to be converted into new, evidence-based practice approaches

CONCLUSION

Investing in these listed opportunities and future priority areas, will signpost the possibility of real innovation, safe and sustainable change, not only for the family carer research landscape, but more importantly for the families and carer communities that research purports to be serving.

READER PROVOCATION

Despite inclusion of family carer participants in peer reviewed papers, most of the families and carer research collaborators do not feel adequately represented in research. Why might this be?

In the broad social context of increasing calls for 'lived experience experts' to join research projects, what are the universities and research centres doing to ensure there are leadership roles for carers in research, to actively, safely and equitably engage family carers in all aspects of research – including publication? We wonder what you and your organisation is committing to in driving change?

We often hear people in furious agreement that "we can't be what we can't see", yet this research identified few papers authored by researchers who claimed 'carer status', how can family carer academic visibility be thoughtfully encouraged ?

GLOSSARY

Consumer/Service user

Is a term commonly used to describe people who have accessed mental health services (VIMIAC).

Family /Carer

A person of any age who, without being paid, provides support to, or is in a 'care relationship' with another person experiencing mental-ill health, including people under the age of 18 years (Victorian State Government, 2021). A carer may, or may not, live with the person they are supporting, and could be a partner, family member, friend, or other support person who provides emotional, spiritual or practical or material supports.

Family carer perspective researcher

A person who works either in a dedicated or designated carer research position, and demonstrably (explicitly) uses their lived mental health carer expertise in their work.

Grey literature

Grey literature is literature that is not formally published in sources such as peer reviewed journals or books. Rather it is material that might be found in magazines, government or industry funded reports, unpublished studies, student projects or community organisational reports.

Researcher with lived experience of family caring

A researcher whose main focus sits within another discipline, but has their own experience of caring/ supporting someone with mental health challenges, and may draw on those experiences to inform their work.

Carer peer academic

Carer peer academic is a carer who engages in research (either as part of a research team and/or co-author) but is not part of the university system. They are also employed by a mental health service in the carer workforce.

SUGGESTED 1:1 INTERVIEW QUESTIONS

Question: From your own experiences, what do you see as the overall state of family carer research in Victoria and beyond? Prompt: The term 'state' could include (but is not limited to) the volume, type (grey vs peer reviewed), focus, age/maturity or content of research.

Question: What do you think makes impactful family carer research?

Prompt: we recognise that the term good is subjective, it could mean 'most relevant' to carers', or most innovative, or most 'easily translatable' or 'impactful'.

Question: From your experience, what key ingredients make up 'good family carer research process and outcome'? Prompt: How do you identify 'good' research process.

Question: From your own experiences and expertise what are some of the biggest (real and hoped for) opportunities for innovation within family carer research?

Question: What do you consider to be some of the biggest gaps in current family carer led and focused research?

Question: What do you see as the consequences of those gaps?

Question: Is there anything else we haven't discussed that you would like to talk about?

SUGGESTED FOCUS GROUP QUESTIONS

Question: We invite you to share your initial thoughts on the 'state' / 'nature' of family carer (led and focused) research in Victoria and beyond. Reminder that the responses can be verbal or written in the chat. Prompt: The term 'state' could include (but is not limited to) the volume, type (grey vs peer reviewed), age/maturity or content/focus of research.

Question: What do you consider to be some of the biggest gaps in current family carer led and focused research?

Question: Over the years, many of us have participated in research. As a family carer research participant, what does good research feel like? Prompt: How can you identify 'good' research process.

Question: What are some of the barriers and enablers to family carers engaging and leading in research?

Question: There is a lot of peer-reviewed research in the family carer space yet a narrative still persists that there is no research, why do you think this research is being overlooked?

Question: Is there anything else we haven't discussed that you would like to talk about?

ESSENTIAL ELEMENTS FOR WORKING WITH CARERS IN RESEARCH

The link to the essential elements for Family & Carer researchers and community members can be found here

DATA

Table of charted literature can be found here Scoping Review table.xlsx

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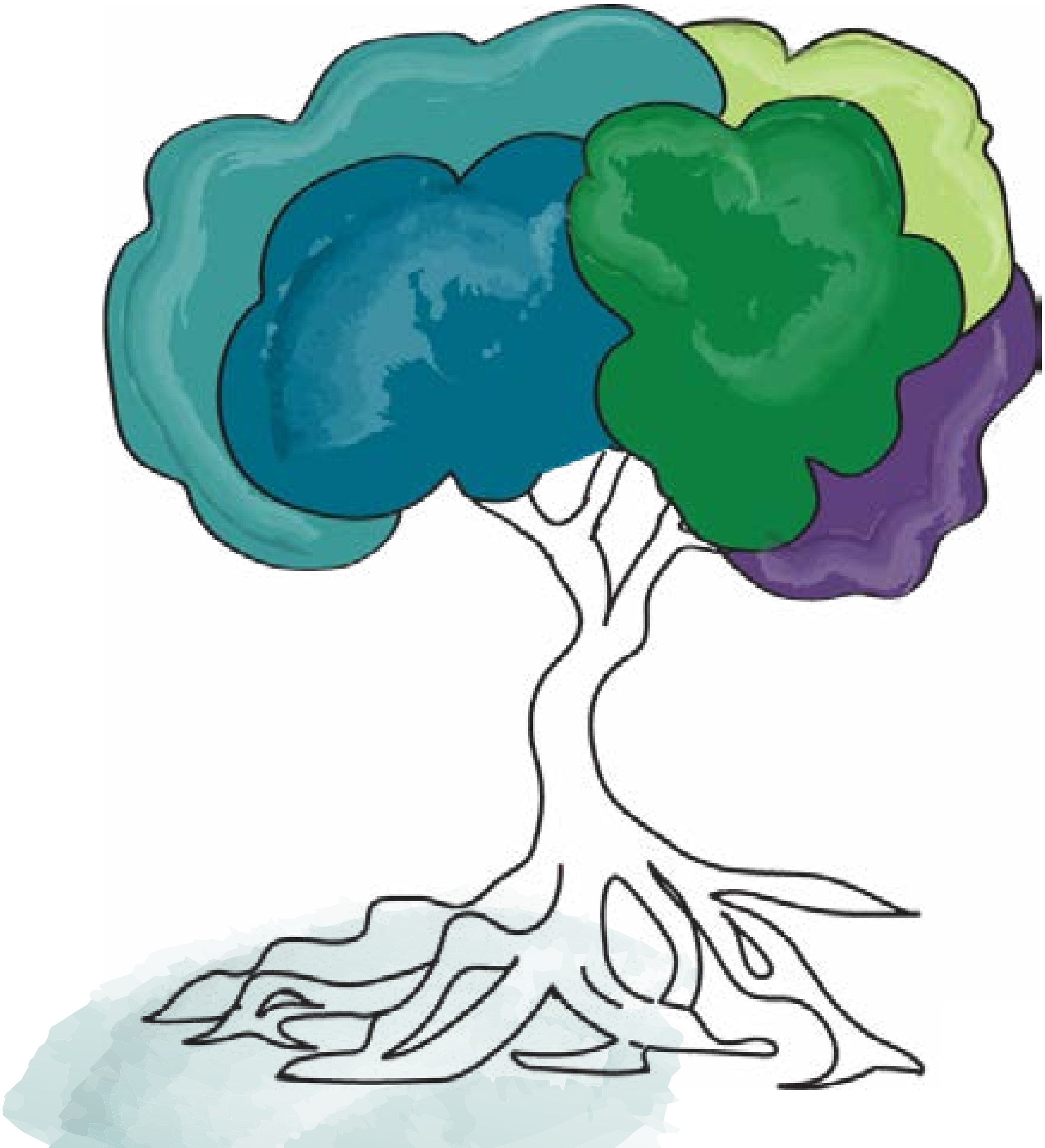

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