SERVICES AND PROGRAM ENTRY

CATEGORY: Short Term Initiatives and Projects

ENTRY TITLE:

Mental Health Family Carer Experiences during COVID-19: navigating complexity/diversity within a co-produced Australian national study

NAME OF APPLICANT:

SWITCH Research Group, Monash University

National Mental Health Consumer and Carer Forum

ORGANISATION:

SWITCH Research Group, Monash University

National Mental Health Consumer and Carer Forum

Additional Information about Entry

For people experiencing mental health challenges prior to the COVID-19 pandemic, additional psychosocial distress resulted from restrictions to movement, reduced and changed clinical service availability, loss of trusted support workers, and difficulties accessing clinical spaces and hospitals. Subsequently support became focused within the person's and the family home. Family carers (people who are in significant relationships with a consumer be they family, friend, neighbour or co-tenant), became providers of additional support and care when mental health services closed.

During the pandemic, the National Mental Health Pandemic Plan identified ten vulnerable population groups. Subsequently in June 2021, the National Mental Health Commission funded ten projects investigating the impact of the COVID-19 Pandemic on different communities in Australia. The National Mental Health Consumer and Carer Forum was funded to investigate how the COVID-19 pandemic impacted the mental health and wellbeing of mental health family, carers and supporters, and following a comprehensive tender process, engaged SWITCH Research Group, Monash University. In January 2022, the partnership commenced working closely together to co-produce the process, clarify the question and to understand what types of information was required to inform the ten requested recommendations to Government. Both consumers and carers were curious about how the changes arising from the pandemic impacted the mental health and wellbeing of family carers.

The co-researchers engaged with mental health family carer organisations and individuals in every state and territory. Additionally, spoke with priority populations of young people, aging people, LGBTQI+ community, Aboriginal and Torres Strait Islander people, CALD communities, veterans alongside people who could speak to the impacts of supporting people who experience AOD use, suicidal behaviour, and justice system challenges. The National Project Steering Group participated in 6 cycles of coproduction: engagement; literature review; co-design of focus group protocol and national survey instrument; data collection; interpretation of results; and preparation of final report and dissemination strategy.

The closure and restrictions on services led to family, carers and supporters needing to provide extra hours and complexity of support: at times constant support, including maintaining the safety of the person through monitoring emotional and physical needs. Many families spoke of the challenges of providing support within community and service restrictions and across borders. The impact of these burdens arising through inadequate systemic responses led to isolation, being overwhelmed, physical and emotional distress and reported thoughts of suicide. The pandemic highlighted prior areas of systemic support that had been missing and also the loss of services that had been of benefit to the consumer and family supporters.

Understanding the experiences and impact on family carers during this sudden change in role and responsibility is vital to future considerations for governments and policy makers in current and future pandemic and disaster planning..

Address the following Criteria

1. **Evidence of a significant contribution to the field of mental health on a local, state or national level.**

The National Pandemic Mental Health and Wellbeing Response Plan was released in 2020 to guide the Australian health sector response to the COVID-19 Pandemic. The Plan identified specific challenges to mental health and wellbeing associated with the COVID-19 pandemic and a range of measures to address the challenges, including noting specific vulnerable populations more likely to have mental health and wellbeing challenges. One vulnerable population group identified in the Australian National Mental Health Pandemic Plan was informal/unpaid carers. There are more than 240,000 people in Australia who are informal/unpaid mental health carers. Carers are known to have poorer mental health than the general population and the Pandemic exacerbated this.

In June 2021 the National Mental Health Commission (the Commission) funded ten projects investigating the impact of the COVID-19 Pandemic on different communities in Australia. The Commission funded the National Mental Health Consumer and Carer Forum to nominate a group in need of support and understanding about their experiences during the COVID-19 pandemic. A decision was made to investigate the impact of the COVID-19 pandemic on the experiences and mental health and wellbeing of family, carers and supporters of people with mental health challenges. The National Mental Health Consumer and Carer Forum commissioned the Social Work Innovation, Transformation and Collaboration in Health (SWITCH) Research Group located within Monash University, Faculty of Medicine, Nursing and Health Sciences to support this project. Caroline Walters, worked alongside SWITCH research group director Associate Professor Melissa Petrakis, to establish a co-production process working with the National Mental Health Consumer and Carer Forum.

The findings of this national project are a significant contribution to the field of mental health on local, state and national levels, with the resulting recommendations being relevant to improving mental health and wellbeing for consumers and family. This project found the COVID-19 pandemic increased the level and complexity of support provided by mental health family carers. The closure and restrictions on services led to family, carers and supporters needing to provide extra hours and at times constant support, including maintaining the safety of the consumer through monitoring both emotional and physical needs. Many families spoke of the challenges of providing support within community and service restrictions and across borders. The deeply felt negative impacts of these burdens arising through systemic failures led to isolation, feelings of being overwhelmed, physical and emotional distress and reported thoughts of suicide. The COVID-19 pandemic highlighted prior areas of systemic support that had been missing and also the loss of services that had been of benefit to the consumer and family supporters.

The resultant recommendations, developed through the voices and experiences of families and consumers, address the difficulties experienced through services not engaging with the consumer's support system, the lack of systemic support in helping families maintain a quality of life within their society/community, and the approaches of therapeutic support that aren't helpful. The 10 recommendations include 5 in the short term which could be actioned in 6 to 12 months. However, many of the recommendations echo and extend calls for change documented in previous policy documents including the A National Framework for Recovery-oriented mental health services (Department of Health and Ageing, 2013) and the more recent Mental Health, Report no. 95 (Productivity Commission, 2020).

The co-production of the final report resulted in a document that closely and authentically speaks to the experiences of people living in families in distress. This report - Petrakis, M. and Walters, C. (2022). Mental Health Family Carer Experiences of COVID-19 in Australia: Final report for the National Mental Health Commission from the NMHCCF as part of the Pandemic Grants for Priority Groups. Sits on the National Mental Health Consumer and Carer Forum's webpage and can be used by Governments, policy makers and services to understand how they can support family carers and consumers.

The Summary Report of Pandemic Research Grants indicated that in recognising pandemics and disasters are likely to occur more frequently, the findings from the Pandemic Grants for Priority Groups highlight the ongoing need to: maintain the support that communities are accessing, uplift where more support is needed, rebuild where connections have been lost or disrupted, and prepare for future disasters, and intentionally learn from what has been experienced through the pandemic.

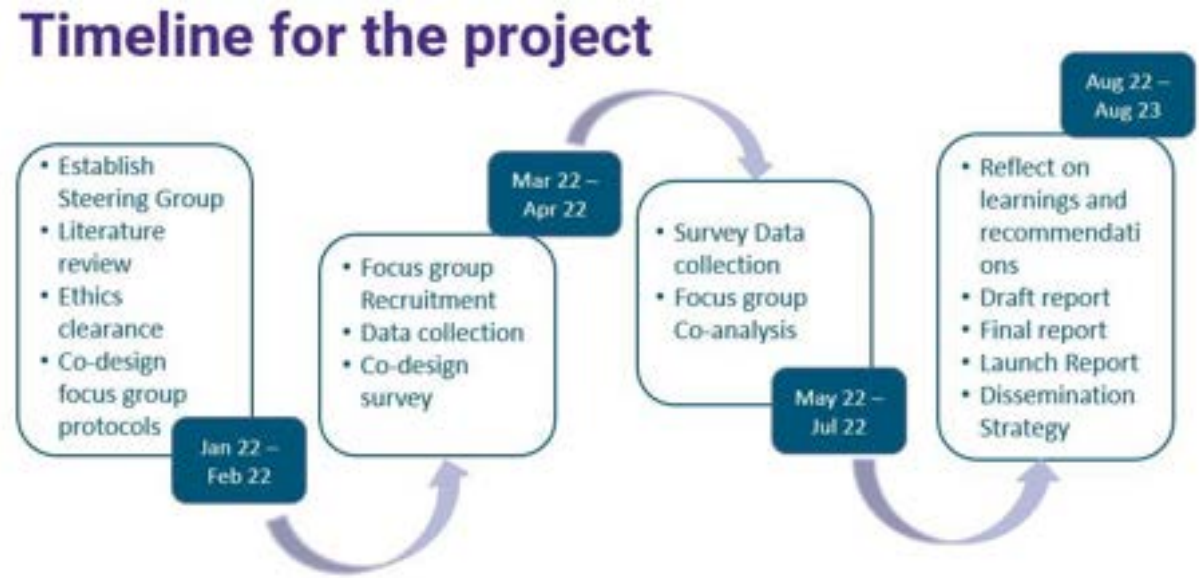
This project's findings fed into the report and demonstrated further significant contribution to the field of mental health on a local, state or national level, through the easily accessed resources including a co-produced summary infographic - Mental Health Family Carer Experiences of COVID-19 in Australia. A recording of the National Public Launch of the report, alongside videos of the significance of the report and recommendations to people who participated in the project. All these resources are publicly available on the NMHCCF site.

2. Evidence of innovation and/or recognised best practice.

From its inception, this project was co-designed and co-produced with mental health family carers and consumers based on their expertise in understanding their experiences and ways to best explore these to the benefit and wellbeing of family carers. Coproduction in the project, which included people at the heart of the research interest, led to distinct advantages in creating more appropriate recruiting, the ability to empathise with the experiences of participants and ensured the processes and content were meaningful, supportive, and safe.

Phases of the project included;

1. Establishing co-production framework and project steering group
2. Co-designing the process for the focus groups, the content and flow of the online survey, and the ethics approval
3. Gathering data through co-facilitated focus groups
4. Gathering data through the co-designed online survey
5. Data analysis and determination of findings
6. Co-reflection, establishment of recommendations, and co-creating the dissemination strategy and social action agenda.



When asked about what they felt was different in this project, one member responded:

> *I guess my lasting reflection, was that the approach gave the time to really work through all of the issues. And, I mean, it was, it was quite lengthy process. And when each of the areas of the survey was discussed, it really went into a lot of detail. So, a lot of discussion, line by line, question by question. Questioning the language, the tone, the assumptions, that were in the question. So that was just that level of each individual question, let alone some of the more, you know, sort of overarching approaches, should it be a survey, who should be involved. But, you know, getting down to actually what was being asked and how it was being asked to ensure that it was respectful. And that it was really based on what was important and relevant for people living through COVID, supporting someone with a mental health condition.*

An evaluation of the co-production process highlights the innovative approaches in the project in the funding of lived experience projects, guidelines for finding university partners, establishing working processes with roles that draw upon the expertise of the members of the project collaboration, dissemination of the findings through co-authoring and co-presenting.

One project team member highlighted the benefits:

> *I think it has been really helpful and validating for each person, that's been a part of the process. There are benefits in how we feel about and feel connected to the research and the data and what we can then do with that… it enriches our understanding for our own practice, whatever we're doing, as lived experience workers, carer supporters out in the community… Now we can say with confidence, I was tugging on government skirts, saying carers are distressed, and they're [Government] going we don't know that. And why do they not know that? Because there was no research, evidence-based studies that were telling them the story. And so now we have something that we can take forward and utilise to tell the story. We spoke to Carers around Australia, not just in one little location, but around Australia from a diversity of backgrounds. And they were telling us this is an issue, that story has weight. So for me, the benefit is the connection to the story and the evidence and what we can do with that, but also our own personal validating experience and growth in our understanding of how to do research and in a co-design model.*

3. **Evidence of participation of mental health consumers in the planning, implementation and evaluation of mental health service delivery.**

Lived experience participation occurred from the inception, with the National Mental Health Commission granting the funds to the National Mental Health Consumer and Carer Forum to choose who they wanted to partner with for the project. Consumers and family carers decided on the question to be investigated and through a tender process determined who and what process would be best to answer.

Through each of the identified phases, lived experience expertise (family carers and consumers) co-designed and co-facilitated the process. At times leading the process, such as in recruitment strategies, and at other times acting as guides. Guidance was provided by lived experience expertise in reflecting upon the literature review to understand what had been researched internationally and what would be important to understand in Australia. The academic partners advised on the possible processes for data collection, and the lived experience experts decided on the methodology based upon that advice. Both the focus group and survey questions were developed and scrutinised from the perspective of the consumers and carers in the project team. Difficult conversations were handled with respect with consumers within the project team gently addressing areas of inquiry that may suggest stigma or feed in to societal stereotypes of people with mental health challenges. Carers were able to consider the wording of questions to still be able to address areas of concern including domestic violence within the family unit and suicide.

The focus groups were co-facilitated by a known carer or consumer, who provided a warm introduction to the two academic researchers, who have experience of being a carer or working closely alongside carers and consumers. Prior to the focus groups occurring, a safe sharing strategy was prepared by the project team through using their experiences and expertise, which was provided to participants before and discussed at the commencement of the focus group.

The data analysis was reviewed by carers and consumers in the project steering group, with the themes from the focus group resonating with their experiences. Recommendations from the project were prepared together with emphasis on the wording to be respectful to both consumers and carers. Dissemination strategies were planned together with carer and consumer representatives being co-presenters at TheMHS 2022 of the preliminary findings. The report for submission to the National Mental Health Commission was written and reviewed together. A committee of consumers and carers, alongside the academic partners, planned the launch of the report in August 2023. The co-authorship of peer reviewed articles has included family carers and consumers from the National Mental Health Consumer and Carer Forum.

4. Evidence of partnerships and linkages with all key stakeholders

The leadership of Caroline Walters and Associate Professor Melissa Petrakis in guiding the process, providing research expertise, and holding spaces for safe interactions alongside the National Mental Health Consumer and Carer Forum (NMHCCF), National and State Peak Bodies and mental health family carer organisations across Australia including, Mental Health Australia, National Rural Health Alliance, MIND Australia, Mental Illness Fellowship, National PHN Mental Health Lived Experience Engagement Network (MHLEEN), Embrace Multicultural Mental Health, The National Aboriginal and Torres Strait Islander Lived Experience Centre – Black Dog Institute, Mental Health Family and Friends (Tasmania), Arafmi Queensland, Helping Minds (Western Australia), Tandem (Victoria), Mental Health Carers (New South Wales), and Mental Health Carers Australia, resulted in enhanced affiliations.

Monthly meetings were chaired by Eileen McDonald (NMHCCF Member) and attended by a full complement of representatives from the above organisations as listed in the table below.

Project Steering Group

Organisation	Representative
NMHCCF	Eileen McDonald (Chair)
NMHCCF	Kerry Hawkins
NMHCCF	Hayley Solich
NMHCCF	Sharon Lawn
NMHCCF	Carli Sheers
Mental Health Australia	JulieAnne Anderson
Mental Health Australia	Emma Coughlan
National Rural Health Alliance	Gabrielle O’Kane
MIND Australia	Nicola Ballenden

Organisation	Representative
Mental Illness Fellowship of Australia	Tony Stevenson
National Mental Health Commission	Rachel Earl and Isabella Bishop
National PHN Mental Health Lived Experience Engagement Network (MHLEEN)	Lynda Watts
Embrace Multicultural Mental Health	Nevena Simic
The National Aboriginal and Torres Strait Islander Lived Experience Centre – Black Dog Institute	Vicki McKenna
Mental Health Family and Friends Tasmania	Maxine Griffiths and Glen O'Keefe
Arafmi, Queensland	Alex Tyson and Ben Tisserand
Helping Minds, WA	Danielle Moore
Tandem, VIC	Amaya Alvarez
Mental Health Carers NSW	Jonathon Harms
Mental Health Carers Australia	Katrina Armstrong

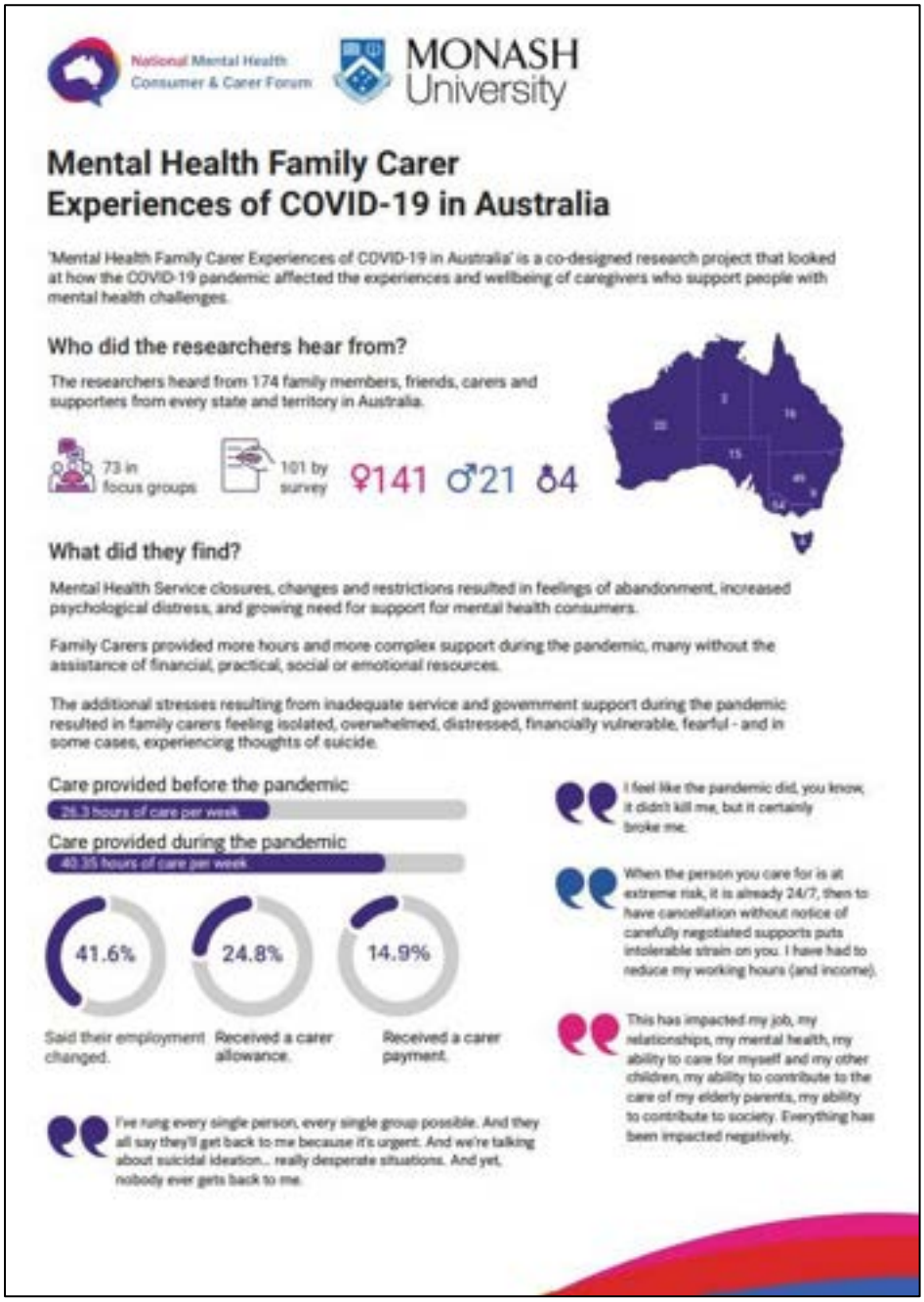
Throughout and following the completion of the project, recognised at the launch of the report, strong partnerships and linkages have occurred and continued through conference presentations, submissions to government, the creation of resources, and co-authoring of peer reviewed articles.

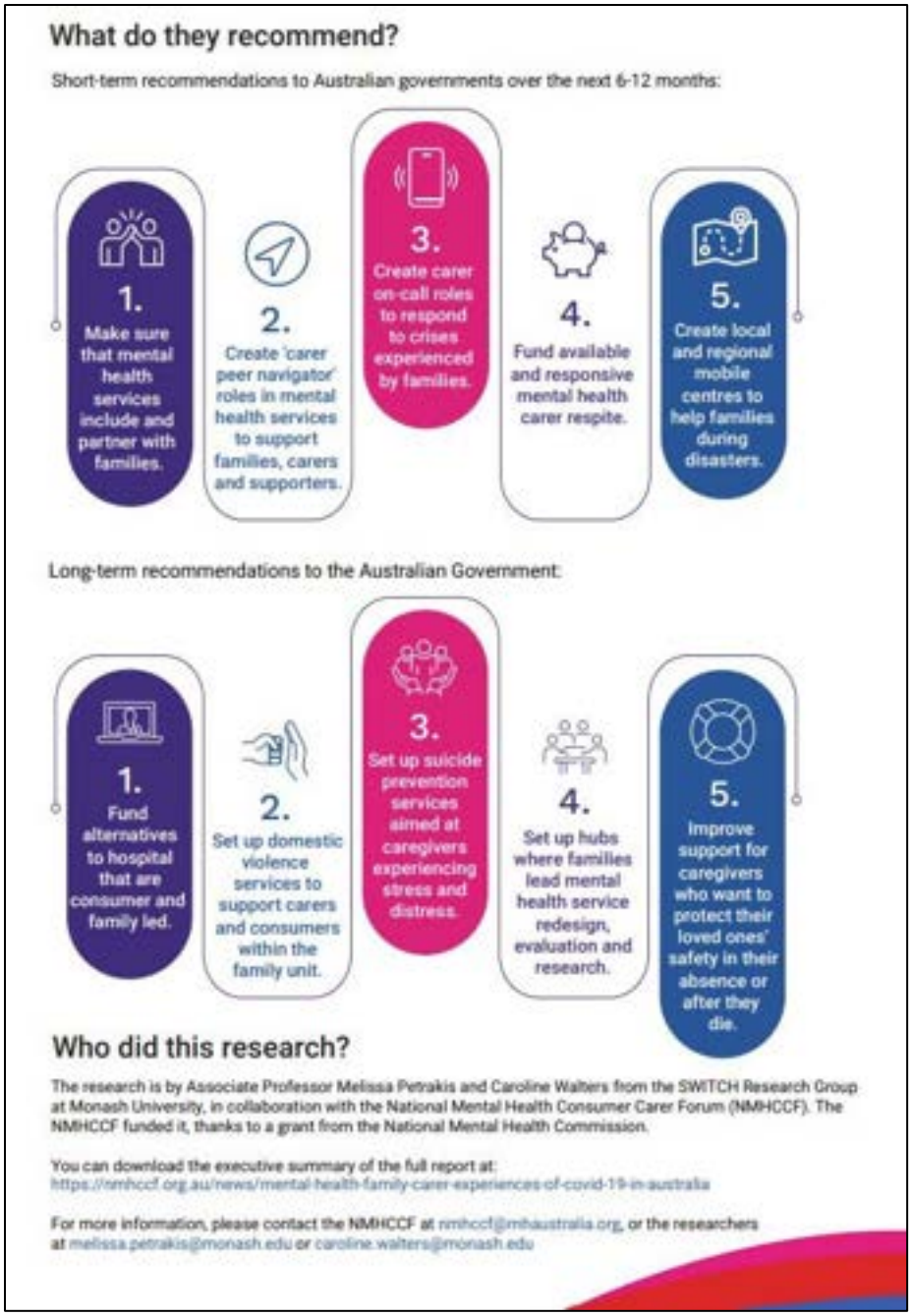
Conference Joint Stakeholder Presentations

TheMHS Forum 2024 (Sydney) – April 2024
Improving the lives of carers and families: What COVID-19 has taught us
The ALIVE National Centre – Annual Symposium
Eposter - Co-production with family, carers and supporters of mental health service users during the COVID-19 pandemic
MHCC ALLIES & ADVOCATES WEBINAR – MARCH 2024
National Research and Advocacy: identifying gaps and opportunities for systemic changes for mental health family carers
TheMHS Conference 2023 – August 2023
Action needed for Family Carer Citizenship Rights in Mental Health System Responses
National Mental Health Consumer and Carer Forum Report Launch
Mental Health Family Carer Experiences of COVID-19 in Australia
6th International Conference on Practice Research (Denmark) – June 2023
Mental Health Family Carer Experiences during COVID-19: navigating complexity and diversity within a co-designed and co-produced Australian national study
TheMHS Conference 2022 – October 2022

Carer Forum: *Interactive Symposium/Panel - Mental Health Family /Carer Experiences of COVID, National Co- Designed National Mental Health Consumer & Carer Forum (NMHCCF)/ Monash Research Project*
LEAD PRESENTATION: *Mental Health Family Carer Experiences of COVID-19: A co-produced National study revealing complexity and diversity*
Carers WA Conference 2022 – October 2022
COVID-19 impacts on Mental Health Carers: Understanding the experiences of mental health carers during the pandemic

Co-production of the Project Infographic





5. Verification of effectiveness

Enduring positive outcomes from this project have been the ongoing work between the SWITCH Research Group and the National Mental Health Consumer and Carer Forum in disseminating the findings and promoting social action to raise the expertise and voices of mental health family carers. In collaboration the results were presented at The Mental Health Services Conference (Sydney) – October 2022, both in the Carer Forum: Using Our Power to Make a Difference in a Complex World – Interactive Symposium/Panel - Mental Health Family /Carer Experiences of COVID, National Co- Designed National Mental Health Consumer and Carer Forum (NMHCCF)/ Monash Research Project; and as a Lead Presentation: Mental Health Family Carer Experiences of COVID-19: A co-produced National study revealing

complexity and diversity. The collaboration has produced a final report (listed below), an easy-to-understand Infographic, which were both launched Nationally on the 31st August 2023, with the Honourable Emma McBride - Assistant Minister for Mental Health and Suicide Prevention and Assistant Minister for Rural and Regional Health, providing a 10-minute review of the report.

The guidance and leadership provided by the university partners, Melissa Petrakis and Caroline Walters, in working alongside the National Mental Health Consumer and Carer Forum has resulted in increased co-research capabilities including understanding research processes and design, data analysis and co-writing, including writing peer reviewed articles (currently under review) for the participants within the project.

Publications from Project

Walters, C. and Petrakis, M. (2022). Mental Health Family Carer Experiences during COVID-19: A Rapid Scoping Review of the International Literature, *The British Journal of Social Work,* Volume 53, Issue 3, April 2023, Pages 1483–1505

Abstract: Internationally, people experiencing mental health challenges and psychosocial distress faced service disruptions, increased uncertainties and isolation, during the COVID-19 pandemic. Mental health family carers in turn experienced high levels of demand to fill gaps in service responses within a context of fear and uncertainty. A scoping narrative review methodology was undertaken to account for the varying methodologies of studies and the recency of the COVID-19 pandemic. Six databases were searched: Proquest, Ovid, Psych Info, CINAHL, Scopus, WHO COVID-19 database in January 2022. A total of 147 articles were identified, with 19 included in the final review. Findings revealed few studies focused on the experiences of mental health family carers during the pandemic. Studies that elevated mental health family voices identified they were more likely to provide emotional support than other carers, and less likely to receive government income support. Higher distress was present in family carers who lived with people with low independence, supported more than one person and provided higher levels of care. Family carers experienced concerns about—family members becoming infected during hospitalisations, accessing services, inappropriate and early discharges, care provision if family carers became unwell and the need for targeted responses and quality for online services.

Walters, C., Solich, H., Lawn, S., McDonald, E. and Petrakis, M. (2024). Families Supporting People with Mental Health Challenges during the COVD-19 Pandemic: Learnings from a Co-designed and Co-delivered Study. *International Journal of Care and Caring*

Abstract: The significant demand for and reduction in mental health services during the COVID-19 pandemic resulted in family carers providing higher levels, and increased hours and complexity of support. Guided conversations within seven co-designed online focus groups with 73 family carers, representing diverse

communities and ages, explored experiences and desired changes for mental health service provision. Six themes emerged; service users' experiences, effects of system failures and service provisions, impact on carers' health and wellbeing, unmet community needs, responsive innovations, and policy and practice recommendations. Co-producing research with families elevated family voices, and supported carers expressing their experiences, needs and rights.

Articles currently under co-writing

Caring During COVID-19: Outcomes from national research led by family carers

Abstract: Family carers were relied upon to provide support and care to people with mental health challenges when mental health services closed during the pandemic. Service users returned to family homes throughout lockdowns, creating more complex and intense situations of physical and emotional interdependence. This study found that carers were often supporting more than one person and typically supporting people with daily and high-level needs. Caring levels increased to an average of 40 hours a week (up from 26 hours) of support provision with increased complexity. Heightened demands became stress-inducing to the point of mental ill health and suicidality for some family carers. Findings suggest that government policy and pandemic responses were predicated on an unjust assumption that family members would, without financial, practical or emotional resources, fulfil the role of care provision and support to unwell and extremely distressed people with new or ongoing mental and psychological ill health.

An exploration of coproduction principles and processes that establish lived experience expertise in mental health system change.

Abstract: Co-production principles focus on rebalancing power to enable decisions making by those at the heart of change. Power comes in many forms and co-production through a strengths-based approach innovates to influence these forms of power. The aim of the study was to identify the principles and processes of participatory research that establish live experience expertise within mental health system change. Coresearchers reflected and discussed their experiences of a National project, to discover what they saw as successful outcomes, what led to the success of the project, and what is key to future coproduction with people with lived experience.

The process of co-production experienced in this project resulted in people feeling active contributors of their own experiences and skills, the power of the collective stories alongside the power of a National Lens, and the sense of coming together as equals. The initiation of the project by a National consumer and Carer Organisation, enabled them to choose partners that aligned with their values and goals for the project and for group members to be part of the whole project from the commencement to dissemination. Coresearchers valued a number of processes and principles that led to the coming together in extended partnership and remaining true to co-design despite time pressures.

Conclusion

Through a grant from the National Mental Health Commission, National Mental Health Consumer and Carer Forum (NMHCCF) commissioned Social Work Innovation Transformation and Collaboration in Health (SWITCH) Research Group, Monash University to provide support in understanding the impact of the COVID-19 pandemic on the experiences and mental health and wellbeing of family, carers and supporters of people with mental health challenges – one of ten vulnerable populations identified in the National Mental Health Pandemic Plan. From its inception, this project was co-designed and co-produced with mental health family carers and consumers based on their expertise in understanding their experiences and ways to best explore these to the benefit and wellbeing of family carers. Coproduction in the project, which included people at the heart of the research interest, led to distinct advantages in creating more appropriate recruiting, the ability to empathise with the experiences of participants and ensured the processes and content were meaningful, supportive, and safe.

The strong partnership between the NMHCCF and SWITCH co-produced authentic evidence to inform 10 recommendations within local, state, and national service systems, which will significantly contribute to the improved lives of consumers and carers. The enduring positive outcomes from this project include the ongoing work between the SWITCH Research Group and the National Mental Health Consumer and Carer Forum in disseminating the findings and promoting social action through the 10 recommendations, and raising the expertise and voices of mental health family carers and consumers. Evaluation of the coproduction process, with shared leadership between a community body and an academic partner, has shown increased co-research capabilities for the participants within the project including understanding research processes and design, data analysis and co-writing peer reviewed articles (published and under review). This family carer and consumer initiated and led project has resulted in publications and a dissemination process that closely and authentically speaks to the experiences of people living in families in distress.

Appendix of Support Material

Co-production with family, carers and supporters of mental health service users during the COVID-19 pandemic

Caroline Walters
Monash University
PhD Candidate
Eileen Mc Donald
[Affiliations]

Associate Professor Melissa Petrakis
Monash University

The ALIVE National Centre for Mental Health Research Translation

Introduction
Withdrawal of and changes to mental health services and other factors arising from COVID-19 such as fear of illness and death, lockdowns, social distancing policies, adversities including loss of employment, domestic conflict and violence resulted in substantially more pressure for families to provide much needed support (Walters and Petrakis, 2022). The National Mental Health Commission funded ten organisations to undertake separate Pandemic Plan Priority Populations Research grants to better understand the unique impact of the pandemic on key priority populations. Through a coproduced study Monash University worked alongside the National Mental Health Consumer and Carer Forum to understand family carer perspectives, experiences and needs in relation to the impact of COVID-19 in Australia.



Methods
Partnership has been foundational to the approach. A national Project Steering Group was established, representing diversity and complexity in mental health, including the NMHCCF carers and consumers alongside national and state organisations with mental health carer expertise, and organisations representing regional, rural and remote, multicultural and Aboriginal and Torres Strait peoples. Two methods of data collection were coproduced being an online survey and co - facilitated focus groups planned for each state, also a national focus group with Embrace representing multicultural communities across Australia. The triangulation of the data enabled a depth of authentic exploration of family carer experiences.

Results or Findings
The researchers heard from 174 family members, friends, carers and supporters from every state and territory in Australia (see map). There were 73 family carers in the focus groups and 101 respondents to the survey. The majority of respondents identified as female (141), with 21 identifying as male and 4 identifying as non-binary. Ages ranged from 18 to 80 years.
This research project found the COVID-19 pandemic increased the level and complexity of support provided by mental health family carers. The closure and restrictions on services led to family, carers and supporters needing to provide extra hours and at times constant support, including responding to and maintaining the safety of the consumer through monitoring both emotional and physical needs. Carers provided more hours and more complex support during the pandemic, often without the assistance of financial, practical, social or emotional resources. Many families spoke of the challenges of providing support within community and service restrictions and across borders. The impact of these added support pressures arising through systemic failures led to isolation, feelings of being overwhelmed, physical and emotional distress and reported thoughts of suicide. The COVID-19 pandemic highlighted prior areas of systemic support that had been missing and also the loss of services that had been of benefit to the consumer and family supporters. Family carers also expressed deep appreciation when trusted services and providers remained engaged and were able to identify measures that would assist in future disaster responses. Together the NMHCCF and Monash University researchers developed 5 short-term and 5 long-term recommendations.

Short term recommendations – 6 to 12 months



Long term recommendations



Key highlights
In the words of family carers:
- I feel like the pandemic didn't, you know, didn't kill me, but it certainly broke me
- I've rung every single person, every single group possible, and they all say they will get back to me because it's urgent…and yet nobody gets back to me.
- When the person you care for is at extreme risk, it is already 24/7, then to have cancelation without notice of carefully negotiated supports it puts intolerable strain on you.

Conclusion
The global movement to treatment within the community without additional resources, has led to greater reliance on family to support individuals who experience mental health challenges. Evidence indicates family carers are often excluded from planning and treatment and do not receive the needed support or education to be able to fulfil their support roles. Subsequently the mental and physical health of family are adversely affected. The COVID-19 pandemic exacerbated the impact on family carers, and understanding these experiences enables greater support for them and the people with whom they are in care relationships.

References
Walters, C., & Petrakis, M. (2023). Mental Health Family Carer Experiences during COVID-19: A Rapid Scoping Review of the International Literature. The British Journal of Social Work, 53(3), 1483-1505

We acknowledge the Traditional Owners of the land on which we work, and pay our respects to the Elders, past and present. The ALIVE National Centre for Mental Health Research Translation is funded by the National Health and Medical Research Council Special Initiative in Mental Health GNT2002047.

MONASH University

National Mental Health Consumer & Carer Forum

Mental Health Family Carer Experiences of COVID-19 in Australia



EXECUTIVE SUMMARY

Summary

This research project found the COVID-19 pandemic increased the level and complexity of support provided by mental health family carers. The closure and restrictions on services led to family, carers and supporters needing to provide extra hours and at times constant support, including maintaining the safety of the consumer through monitoring both emotional and physical needs. Many families spoke of the challenges of providing support within community and service restrictions and across borders. The impact of these burdens arising through systemic failures led to isolation, feelings of being overwhelmed, physical and emotional distress and reported thoughts of suicide. The COVID-19 pandemic highlighted prior areas of systemic support that had been missing and also the loss of services that had been of benefit to the consumer and family supporters.

The National Mental Health Consumer Carer Forum (NMHCCF) engaged **SWITCH Research Group, Monash University** as the research partner to work with the Project Steering Group to co-design and co-produce data gathering and data analysis, including: development of tools; preparation of project resources; data gathering and analysis; and with the preparation of the final report. Through state focus groups and a national survey, the researchers investigated the significant adverse impact on mental health carers, their overall experiences, levels of distress, unmet needs and their caring responsibilities due to and during the COVID-19 pandemic.

Recommendations

The following recommendations have been developed through the voices and experiences of families which have been adversely impacted by the COVID-19 pandemic, but also speak of difficulties experienced through services not engaging with them or lack of systemic support in helping them to maintain a quality of life within their family and society/community. The 10 recommendations include 5 in the short term which could be actioned in 6 to 12 months. However, many of the recommendations echo and extend calls for change documented in previous policy documents including the *A National Framework for Recovery-oriented mental health services* (Department of Health and Ageing, 2013) and the more recent *Mental Health, Report no. 95* (Productivity Commission, 2020).

Short term

1. Australian governments to review practices in inpatient and other clinical settings to ensure family inclusion and partnership in supporting people with mental health challenges.
2. Australian governments to fund the creation of carer peer navigator roles – providing information and support – across inpatient and community services for families, carers and supporters.
3. Australian governments to prioritise the creation of carer support on-call roles, accessible via local and regional mental health triage services, to respond to crises experienced by families.
4. The Australian Government to fund available and responsive mental health carer respite to ensure carer workload does not overwhelm family members so they are able to remain in paid work.
5. In order to respond to current and future major disasters (pandemics, fires, floods, and drought), Australian governments to create local and regional mobile centres for family

assistance.

Long term

1. The Australian Government funds diverse modalities of consultations and therapeutic interventions to enable mental health consumer and carer choice, inclusive of but not defaulting to teleHealth.

2. The Australian Government, in recognising the risk inherent in providing long-term and acute mental health care on carers, to establish domestic violence services tailored and responsive to family members experiencing acute and/or cumulative risk and violence.

3. The Australian Government, in recognising the impact of providing long-term and acute mental health care on the psychosocial wellbeing of carers, to establish suicide prevention services responsive to family members experiencing acute and/or cumulative stress and distress.
4. The Australian Government to establish funded family-carer collaborative hubs to foster, mentor and disseminate family leadership in service redesign, evaluation and research.
5. The Australian Government to provide national guidance and co-ordination for innovation across all states in administration and guardianship as it relates to mental health carers concerned about the safety of loved ones in their absence or upon their death.

What our research is about and why it is important

During the Covid-19 pandemic, one vulnerable population group identified in the National Mental Health Pandemic Plan was informal/unpaid carers. There are more than 240,000 people in Australia who are informal/unpaid mental health carers. Carers are known to have poorer mental health than the general population and the Pandemic exacerbated this. In June 2021 the National Mental Health Commission (the Commission) funded ten projects investigating the impact of the COVID-19 Pandemic on different communities in Australia. This project was selected as part of that process to investigate how the COVID-19 pandemic impacted the mental health and wellbeing of mental health family, carers and supporters.

In Australia, (Diminic et al., 2019) published 'A profile of Australian mental health carers, their caring role and service needs: results from the 2012 Survey of Disability, Ageing and Carers'. Results were: In 2012, there were 225,421 co-resident carers of adults with mental illness in Australia, representing 1.0% of the population, and an estimated further 103,813 mental health carers not living with the care recipient. The majority of co-resident carers supported one person with mental illness, usually their partner or adult child. Mental health carers were more likely than physical health carers to provide emotional support (68.1% v. 19.7% of carers). Many primary mental health carers (37.8%) provided more than 40 hours of care per week. Only 23.8% of primary mental health carers received government income support for carers and only 34.4% received formal service assistance in their caring role, while 49.0% wanted more support. Significantly more primary mental health than primary physical health carers were dissatisfied with received services (20.0% v. 3.2%), and 35.0% did not know what services were available to them.

What did we want to find out?

The research objectives of the project were to:

• Gather evidence on the impact of the Covid-19 pandemic on levels of mental health carer distress in Australia

Appendix of Support Material

• Identify Australian mental health carer unmet needs arising from the Covid-19 pandemic.

What did we do?

The researchers engaged with mental health family carer organisations and individuals in every state and territory. Additionally, spoke with priority populations of young people, aging people, LGBTQI+ community, Aboriginal and Torres Strait Islander people, CALD communities, veterans alongside people who could speak to the impacts of supporting people who experience AOD use, suicidal behaviour, and justice system challenges. National Project Steering Group participated in 6 cycles of codesign: engagement; literature review; co-design of focus group protocol and national survey instrument; data collection; interpretation of results; and preparation of final report and dissemination strategy.

What did we find out?

- Family carers reported there were repeated if not routine breaches of family carer rights to access treatment and support for themselves and their unwell family members during the COVID-19 pandemic and access was worse than usual
- Rigid adherence to inconsistent and changeable health directions resulted in high levels of family carer distress and powerlessness over the prolonged period of the pandemics (more than 2 years)
- Family felt invisible and broken during the COVID-19 pandemic by the deepening of existing exclusion from clinical care planning – the value of a sense of connection was highlighted and emphasised as a preferred way to be treated
- Despite challenges experienced many families utilised restrictions on movement and activities to connect deeply with household and community members
- Government policy and pandemic responses were predicated on an unjust assumption that family members would, without financial, practical or emotional resources, fulfil the role of care provision and support to unwell and extremely distressed people with new or ongoing mental and psychological ill health.

Opportunities from our research

This project demonstrated the capacity of the NMHCCF to co-lead, co-develop research and the value of findings which authentically include family carer voice and experiences.

This project demonstrated the capability of SWITCH research group – and more specifically – Melissa Petrakis and Caroline Walters – to mentor co-design and co-produce lived and living experience research immersed in family carer and consumer expertise.

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