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Evaluation of NSW Family and Carer Mental Health Program: Final Report

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Evaluation of NSW Family and Carer Mental Health Program: Final Report

Abstract

This is the final report of the evaluation of the Family and Carer Mental Health Program (FCMHP). The evaluation was commissioned by the NSW Ministry of Health (the Ministry) and undertaken by the Centre for Health Service Development (CHSD), Australian Health Services Research Institute (AHSRI), University of Wollongong. It is the first evaluation of the FCMHP since it commenced operating in 2005.

The Ministry commissioned the FCMHP evaluation with the aim of better understanding the achievements of the program and to contribute to the evidence base for family and carers supporting people with mental health issues.

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CHSD
centre for health service development

Evaluation of NSW Family and Carer Mental Health Program

Final Report

January 2022

ahsri
australian health services research institute
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About the FCMHP evaluation reports

Three reports have been produced for the FCMHP evaluation:

- This final evaluation report which includes a detailed breakdown of FCMHP program and carer survey data and an in depth analysis of the qualitative data collected through carer and stakeholder interviews.

- A summary report which provides a detailed overview of the evaluation including summary level analyses of FCMHP program and carer survey data and an overview of qualitative data collected during a series of carer and stakeholder interviews.

- An interim FCMHP evaluation report that was submitted to the NSW Ministry of Health in September 2021.

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Abbreviations used in this report

AHSRI	Australian Health Services Research Institute
CALD	Culturally and Linguistically Diverse
CHSD	Centre for Health Service Development
CI	Confidence intervals
CMO	Community Managed Organisation
DASS	Depression Anxiety and Stress Scale-42
eMR	Electronic Medical Record
FCMHP	Family and Carer Mental Health Program
FTE	Full-time equivalent
InforMH	NSW Health Information for Mental Health
IQR	Interquartile range
JH&FMHN	Justice Health and Forensic Mental Health Network
KPI	Key Performance Indicators
LHD	Local Health District
MDS	Minimum Data Set
MHDAO	Mental Health and Drug and Alcohol Office
MOU	Memorandum of Understanding
NGO	Non-Government Organisation
SLA	Service Level Agreement
the Ministry	The NSW Ministry of Health
TMHC	Transcultural Mental Health Centre
WWF	Working with Families

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Executive summary

There is an abundance of evidence to support the crucial role of carers in providing support for people with mental health issues.[1,2] The NSW Family and Carer Mental Health program was established in 2005 by the NSW Ministry of Health (the Ministry). The program operates as a partnership between the Community Managed Organisation (CMO) sector and NSW Local Health Districts (LHDs) including the Justice Health and Forensic Mental Health Network (JH&FMHN). Five CMOs deliver services across NSW with one responsible for each NSW LHD.

The Family and Carer Mental Health Program (FCMHP) Evaluation

The Ministry commissioned the Family and Carer Mental Health Program (FCMHP) evaluation to better understand the achievements of the program and to contribute to the evidence base for family and carers supporting people with mental health issues.

The evaluation was completed between June 2020 and September 2021 by the Centre for Health Service Development (CHSD), Australian Health Services Research Institute (AHSRI), University of Wollongong. It is the first time that the FCMHP has been evaluated.

The FCMHP evaluation comprised four key components:

- Describe the core elements of the FCMHP and the processes undertaken by participating services in its implementation;
- Collect and analyse information from stakeholders to answer key evaluation questions;
- Understand the impacts of the program and the factors that influence its success and sustainability; and
- Identify the implications of activity to inform future government policy in relation to family and carer inclusive practice in mental health services.

The evaluation used mixed methods exploratory design and was conducted over two phases. Findings from Phase 1 were included in an interim report submitted to the Ministry in March 2021. This final report consolidates the findings from both phases of the evaluation.

The evaluation did not aim to conduct a formal assessment of the program's historical performance. Rather, it sought to evaluate the program's outcomes in the context of identifying opportunities to enhance its ongoing effectiveness.

Data from a wide range of quantitative and qualitative sources informed the evaluation. FCMHP administrative data provided a rich source of information in relation to the demographic, social and well-being profile of carers. In addition, a Carer Experience Survey

[1] Australian Government (2010) 'National Standards for Mental Health Services 2010', *National Mental Health Strategy*, pp. 1–60. Available at: http://www.ag.gov.au/cca.
[2] Mottaghipour, Y. and Bickerton, A. (2005) 'The Pyramid of Family Care: A framework for family involvement with adult mental health services', *Australian e-Journal for the Advancement of Mental Health*. Informa UK Limited, 4(3), pp. 210–217.

was conducted with more than 200 carers providing feedback on their experiences of the program. Qualitative data provided valuable information through 30 interviews with LHDs, CMOs, specialist networks and peak bodies, and 15 interviews with carers currently registered with the program. Extensive historical program documentation was also examined.

Using the available data, the evaluation has assessed the impact and outcomes of the FCMHP at three levels: families and carers, providers and the broader health system. Data have been analysed to develop an understanding of associations between carers' characteristics and the levels and types of support services received, and assess the relative importance of the different types of services offered by the FCMHP.

Key findings

The evaluation has found the program to be widely regarded as an important and successful initiative. It is well established within the mental health sector and recognised as having improved the lives of carers over many years.

Many positive outcomes have been identified during the evaluation. For example, four out of every five carers reported being satisfied with the frequency of their involvement in the FCMHP. Similarly, the vast majority of carers reported they 'strongly agree' or 'agree' that the services and support offered by the FCMHP have a positive impact on their health and well-being (86%) and on the person they support (73%).

In terms of the program's overall objectives, the services delivered by CMOs, LHDs and the JH&FMN have contributed significantly to increasing the capacity of mental health services to work with families and carers of mental health consumers. The program has also directly resulted in a decrease in levels of stress and burden among the carers it supports.

Quantitative data highlight the substantial overall reach of the program. The evaluation analysed 16,540 data items/observations for 6,201 distinct carers supported by the five CMOs across NSW for the period July 2018 to September 2020. It showed that 80% of carers were female and aged over 40. On average, carers received 180 minutes of individual care, 380 minutes of group care and 81 minutes of indirect care over this period.

A longitudinal analysis of the data collected using the Carers Star tool, identified improvements in levels of carer well-being over time. The assessment tool identifies and measures change across seven key areas, using a five point scale that demonstrates the carer's 'journey of change' as measured at different points in time. The results can be used to plan and improve carer support services as well as demonstrating their impact. Positive outcomes were seen in all domains, most notably in the 'Health' domain which had a two-fold increase in 'as good as it can be'/'mostly ok' responses between the first and last assessment (43% to nearly 90%), followed by 'The Caring role' (35% to 60%), 'Time for yourself' (42% to 65%), and 'How you feel' (30% to more than 50%). Similar improvements in carer well-being were also identified from an analysis of 13,811 assessments completed between October 2008 and June 2018 using the Depression Anxiety and Stress Scale-42 (DASS).

These findings are consistent with the results of the Carer Experience Survey, in which the vast majority of more than 200 participants reported that the program had a positive impact on their lives (nearly 90%). Survey participants were also satisfied with how often they were involved in the program (80%).

A synthesis across all evaluation data sources identified a strong body of evidence supporting the positive impact of the FCMHP for families and carers. This included carers' enhanced understanding of the health system empowering them to better support their loved one, and improved self-care skills and capacity to maintain their own health and well-being. Further, the program has contributed to improved family relationships and helped carers develop a better sense of their own value.

A key evaluation finding was a strong sense among stakeholders that the program has embedded the inclusion of family and carers through building participation processes into practice. This has occurred through family meetings, needs assessment processes that include carer needs, and the inclusion of families and carers in support plans. Other examples include carers working directly with clinicians to co-design programs, education and promotion resources. At the same time, stakeholders reported that there is some way to go before carer inclusion is fully embedded in services.

At the provider level, the evaluation identified effective partnership arrangements in place between FCMHP partners. Differences in models of care between LHDs did emerge as a significant issue. While not explicitly raised as a concern by carers, program staff suggested that greater consistency would result in a more strategic and coordinated approach across NSW. In particular, it would allow clinical need to be more easily identified, as well as more appropriately targeting services for groups such as culturally and linguistically diverse (CALD) and Aboriginal and Torres Strait Islander people.

The scope of practice of CMO staff emerged as an issue for carers and program staff across a small number of LHDs. Some carers suggested that upskilling CMO staff to deliver counselling services would meet an important unmet need. In contrast, other stakeholders felt that it is the role of LHDs rather than CMOs to deliver these services. The increasingly important role of peer workers within the program was also broadly recognised as an important and positive outcome for the program.

A further finding was that there are very few identified positions for Aboriginal and Torres Strait Islander staff across the program. A number of important suggestions were identified including recruiting Aboriginal and Torres Strait Islander peers to the program, providing extra resources to build partnerships with Aboriginal and Torres Strait Islander groups and building cultural capacity of program staff and other stakeholders.

In terms of overall resourcing, the evaluation found the program's resources are being utilised efficiently both within and across the program. As expected, almost all providers felt that funding for the program is not sufficient to meet the level of demand for their services. This results in services having to choose which particular elements of the program they provide to carers and mental health services. With increased funding and support, there

could be a more holistic and consistent program delivery which would further improve outcomes and ensure more equitable access. An analysis of the carer profile data does indicate that there is clearly a level of unmet need for services, likely to be greatest in rural and regional areas.

A further output from the evaluation has been the development of a program logic for the FCMHP. The program logic provides a clear summary of the objectives of the program and the interaction between its different elements. It is hoped that it will serve as a practical monitoring and evaluation tool in the future.

The evaluation has also identified opportunities to enhance the program. These are presented as a set of recommendations for the FCMHP moving forward.

Recommendations to enhance FCMHP outcomes at the families and carer level

1. Establish clear and transparent feedback mechanisms including training and program guidelines to encourage carer input and feedback on program design and practice;
2. Implement appropriate minimum training requirements for CMOs staff, including Trauma Informed Practice and group facilitation to ensure carers feel safe and included;
3. Develop strategies/guidelines/requirements for carers to be included in program and local CMO governance and quality improvement processes;
4. Develop strategies and consider minimum requirements to ensure all carers have access to the key elements of the program – i.e., personal support, peer support, peer connections, education.

Recommendations to enhance FCMHP outcomes at the provider level

5. Increase program funding to employ people with lived experience, males, Aboriginal and Torres Strait Islander and CALD people working in the program;
6. Develop resources to ensure the program promotion, design and practice are appropriate for minority groups and others who are currently underrepresented in the program;
7. Ensure that carer peer workers are integrated into the staff profile of the FCMHP providers;
8. Provide additional funding to resource more flexible options for program delivery – e.g. after hours support and education activities, additional outreach support.

Recommendations to enhance FCMHP outcomes at the system level

9. Conduct a formal needs assessment of the FCMHP to quantify levels of unmet need;
10. The program logic be adopted as a resource for the FCMHP;
11. Ensure FCMHP staff undertake initiatives to develop an understanding of how to engage and service marginalised and/or minority groups;
12. Develop a standard suite of resources for the FCMHP, in co-design with carers, with a process for systematic review and update in place;
13. Review LHD data collection and reporting processes in consultation with the LHDs;
14. Utilise the program data collections to assess and further develop the program.

1 Introduction

This is the final report of the evaluation of the Family and Carer Mental Health Program (FCMHP). The evaluation was commissioned by the NSW Ministry of Health (the Ministry) and undertaken by the Centre for Health Service Development (CHSD), Australian Health Services Research Institute (AHSRI), University of Wollongong. It is the first evaluation of the FCMHP since it commenced operating in 2005.

The Ministry commissioned the FCMHP evaluation with the aim of better understanding the achievements of the program and to contribute to the evidence base for family and carers supporting people with mental health issues.

The FCMHP evaluation has comprised four key components:

- Describe the core elements of the FCMHP and the processes undertaken by participating services in its implementation;
- Collect and analyse information from stakeholders to answer key evaluation questions;
- Understand the impacts of the program and the factors that influence its success and sustainability; and
- Identify the implications of activity to inform future government policy in relation to family and carer inclusive practice in mental health services.

The evaluation has addressed four core evaluation questions.

Process evaluation questions:

- Has the FCMHP been effective, efficient and appropriate and what, if any, changes could be made to enhance these outcomes?

Outcome evaluation questions:

- How well have resources been targeted at the identified need and what, if any changes could be made to enhance this?
- What level of 'value-add' has been achieved in relation to improving partnerships with government, Community Managed Organisations (CMOs) and other relevant stakeholders?
- Has there have been any unintended outcomes associated with the operation of the FCMHP?

The FCMHP evaluation has been conducted between June 2020 and September 2021. An interim report was submitted to the Ministry in March 2021. The evaluation findings presented in this final report cover the entire evaluation period.

Data sources that have contributed to the evaluation include historical documentation, FCMHP program data spanning a 12 year period, a range of stakeholder interviews and a survey of FCMHP family and carers. Ongoing liaison with the Ministry and other stakeholders has also occurred throughout the evaluation.

2 Background and context of the FCMHP

The FCMHP is a statewide program funded by the NSW Ministry of Health. It aims to promote and sustain the well-being of families and carers of people with mental health issues and the people they support. The program is delivered in partnership between specialist CMOs, Local Health Districts (LHDs) and the Justice Health and Forensic Mental Health Network (JH&FMHN). The program includes service development and family engagement and support components. The core objectives of the FCMHP are to:

- Improve family and carer coping
- Increase carers' knowledge of mental illness
- Enhance carers' wellbeing, resilience and relationships
- Assist carers in finding services to meet their needs and circumstances
- Provide individual emotional support to carers.

The FCMHP has two main program strategies:

- To increase the capacity of the mental health service to work with families and carers of mental health consumers by:
    - increasing the knowledge and skills of staff to work with families and carers
    - increasing organisational support to work with families and carers
    - developing/ensuring appropriate resources to work with families and carers.
- To improve the wellbeing of families and carers of mental health consumers by:
    - improving the initial linking/engagement of families and carers with the service
    - increasing the knowledge and skills of families and carers
    - increasing support for families and carers.

2.1 A brief history of the FCMHP

A brief history of the FCMHP has been included here to provide an historical context for the current evaluation. It is based primarily on documentation provided by the Ministry and other FCMHP stakeholders. Some details are based on information provided during interviews with key stakeholders.

Program origins

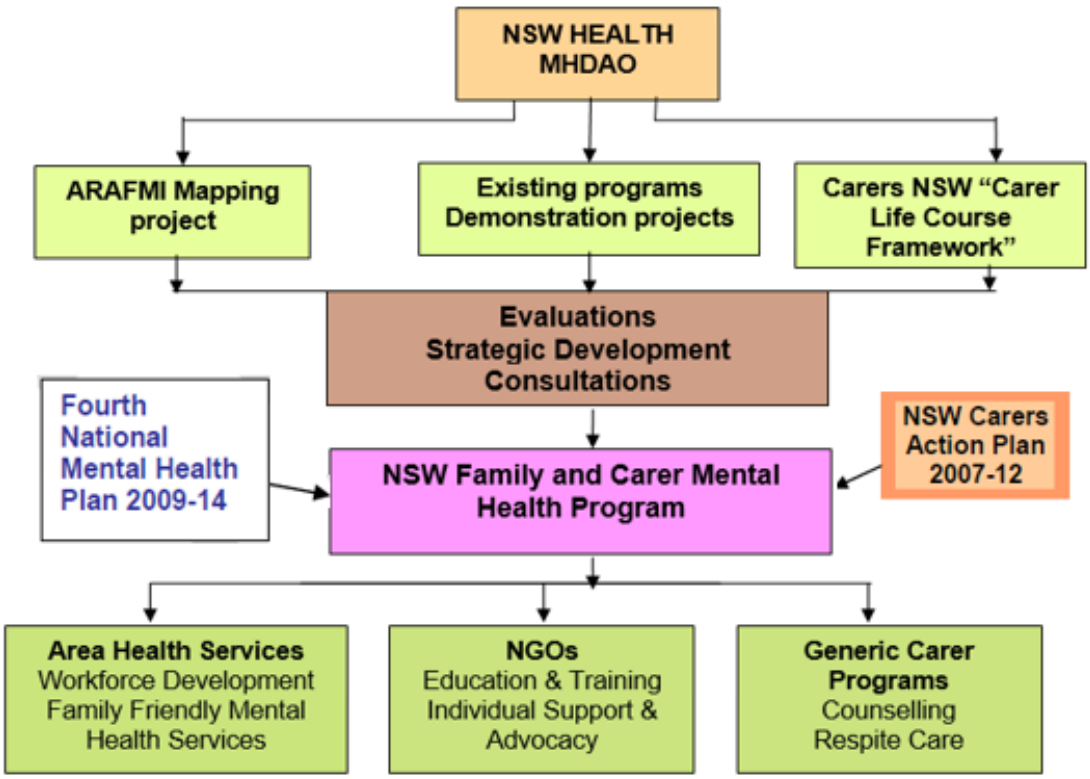
The Working with Families (WWF) program, first established in 1996 at Sutherland Mental Health Service, aimed to increase the capacity of the mental health service to work with families. In 2000, the NSW Caring for Carers Program funded nine mental health specific demonstration projects which covered a wide range of models and priorities. As well, the ARAFMI Mapping Project and the Carers Life Course Framework project were funded to increase the knowledge about what was needed and what worked in the local context. The 'Carers Compass'[3] from King's Fund, UK, also informed the development of the program

[3] Banks P, Cheeseman C & Maggs S (1998) *The Carers Compass: directions for improving support to carers*, King's Fund, UK.

model, and was subsequently adopted as the core of the program. Building on these foundations, the Centre for Mental Health developed the Family and Carer Mental Health Program, and it was officially launched by the Minister for Health on 23 June 2005. The aims of the program were to provide education, support and partnerships with families and carers, to promote family friendly culture and enable clinicians to work in a family/carer framework in adult mental health services across NSW.[4] The Mental Health and Drug and Alcohol branch within the Ministry also established a statewide steering committee to develop, implement and oversee the program. The WWF program conducted training for clinicians and mental health staff across NSW during 2004-2006 as part of the program.

The development of the FCMHP continued, building on strategic documents including, *A New Direction for NSW State Health Plan Towards 2010, the NSW Carers Action Plan 2007-2012*[5] and the *NSW: A new direction for Mental Health* plan[6]. Figure 1 below provides an outline of the development of the FCMHP.

Figure 1 NSW Family and Carer Mental Health Program development [7]



Program funding

As represented in Figure 1, the program addresses the needs of families and carers via three linked components – LHDs (previously Area Health Services), CMOs (previously Non-

[4] NSW Health (2013) *NSW Family and Carer Mental Health Program Framework 2013 Draft.*
[5] NSW Department of Health (2007) *A new direction for NSW: State Health Plan: towards 2010,* North Sydney.
[6] NSW Department of Health (2006) *NSW: a new direction for mental health,* Sydney.
[7] NSW Health (2013) op. cit.

Government Organisations (NGOs))[8], and generic carer supports. The program funds only the first two components. State and federal sources fund mainstream carer support services.[9]

Initially NSW Area Health Services were funded by NSW Health's Mental Health and Drug and Alcohol Office to deliver family friendly mental health services. Area Health Services, through their mental health services, employed specialist family and carer staff, provided local workforce training and development opportunities, and provide access to specialist clinical advice.

The second key component was the funding of NGOs to provide direct support services for families and carers through NGOs. These NGOs were to work in partnership with Area Health Services, carers and families, and other external organisations to deliver services to family and carers.

Ongoing program development

In the years since the FCMHP was launched in 2005, there have been disruptions caused by amalgamation of health regions into Area Health Services, and then again later by the restructuring into the current Local Health Districts, which impacted on the progress of the program development.

A draft program structure document was developed in 2008 but was never issued due to the re-organisation of the health service at critical times for the program. The document was redrafted in 2013 but again was not released. In 2017, the program structure was reviewed again through a workshop process. This structure was then published on the NSW Health FCMHP website.[10]

In the initial FCMHP Framework, funding was provided to four NGOs to provide services in partnership with eight Area Health Services, as outlined in Table 1 below.

Table 1 Initial Area Health Service and NGO partnerships

NGO	Area Health Services
Schizophrenia Fellowship: Carer Assist Program	Hunter New England, Greater Southern, Sydney South West
Carers NSW	Greater Western, North Coast, South East Sydney Illawarra
Uniting Care MH	Sydney West
ARAFMI NSW	North Sydney Central Coast

In 2011, services were retendered when Area Health Services were amalgamated into Local Health Districts. The five successful NGOs providing services in partnership with the 15 LHDs were listed in the 2013 draft program structure (Table 2).

[8] NSW Health (2008) *Framework for the NSW Family and Carer Mental Health Program* DRAFT.
[9] NSW Health (2013) op. cit.
[10] NSW Health (2018) NSW Family and Carer Mental Health Program framework (available www.health.nsw.gov.au/mentalhealth/services/carers/Pages/support-framework.aspx).

Table 2 Restructured CMO and LHD partnerships

CMO (previously NGOs)	Local Health Districts
Schizophrenia Fellowship: Carer Assist Program	Hunter New England, Southern NSW, Murrumbidgee, Sydney, South West Sydney
Centacare	Far West, Western
Aftercare	South East Sydney, Illawarra Shoalhaven
Uniting Care MH	Western Sydney, Nepean Blue Mountains, Central Coast, Northern Sydney
Mission Australia	Northern NSW, Mid North Coast

New agreements were signed in 2013 with Key Performance Indicators (KPIs). These KPIs were updated in 2017-18 and again in 2020 after feedback from CMOs, to reflect populations in specific LHDs, such as Culturally and Linguistically Diverse (CALD) and Aboriginal and Torres Strait Islander populations.

A Minimum Data Set (MDS) was introduced in 2018, in line with the updated KPIs, to provide consistent monitoring of CMO program activities. The Carers Star tool[11] was also introduced as a carer assessment tool for the CMOs, with the data items from the tool included in the MDS.

Data from the MDS collected by CMOs are forwarded to the NSW Health Information for Mental Health (InforMH), the unit responsible for the data collection, analysis and reporting for NSW Mental Health and Drug and Alcohol services.

The LHDs report on the program directly to the Ministry. Initially this was a written summary of the program activity, but since 2019 the data are reported on a template including 4 key data items.

In 2016, in recognition of the need for cultural change, the mental health service began a comprehensive program aimed at positively accelerating change.[12] A new Framework for the FCMHP was developed during a workshop in 2017. The aim was to articulate the program's aims and objectives, stakeholders, partnership arrangements and governance structures. The document was circulated to FCMHP members for feedback before this document was completed and published in September 2017.[13]

Although the program is considered to be successful in its implementation and outcomes, the FCMHP has not previously been evaluated. To this end, the Mental Health Branch of the NSW Ministry of Health commissioned the Centre for Health Service Development, University of Wollongong to evaluate the program over 15 months from July 2020 to September 2021.

[11] Triangle Consulting Social Enterprise Ltd, *Carers Star™ The Outcomes Star for people caring for others* (available www.outcomesstar.org.uk/using-the-star/see-the-stars/carers-star/).
[12] Haisman B (2018) *Carers – a resource worth developing*, Together Achieving Better Health Conference, Nepean Blue Mountains Local Health District, November 2018.
[13] NSW Health (2018) op. cit.

2.2 Current structure and activity of the FCMHP

The FCMHP has been continuously funded by the NSW Government since its commencement in 2005. It currently receives funding under the Mental Health Reform initiatives budget and was most recently allocated approximately $9.5M for the period 1 July 2020 to 30 June 2023. The funding primarily supports the delivery of the program by the CMO partners, with an allocation also supporting positions in the LHDs and JH&FMHN - generally one FTE at each.

Under the current FCMHP arrangements, five CMOs deliver services across NSW with one working in partnership with each of the LHDs. Funding and Performance Agreements for the CMOs funded through the program are centrally managed by the Ministry.

CMOs and LHDs negotiate SLAs for the management and co-ordination of the program, which outline the roles and responsibilities of all. The SLA covers issues such as:

- Governance
- Confidentiality, communication and information sharing
- Resource development and sharing
- Reporting and review
- Risk management.

LHDs and their CMO partners are required to establish a reference or coordination group that has responsibility for the development and coordinated implementation of the program at the local level. Local terms of reference are developed to reflect the specific needs of the area.

The five CMOs currently delivering FCMHP services and their corresponding LHD partners are shown in Table 3.

Table 3 Current CMO and LHD partnerships

CMO	Local Health District
Catholic Care Wilcannia-Forbes	Far West, Western NSW
Mission Australia	Mid North Coast, Northern NSW
One Door Mental Health	Hunter New England, Murrumbidgee, South Western, Southern NSW, Sydney
Parramatta Mission[14]	Central Coast, Nepean Blue Mountains, Northern Sydney Western Sydney
Stride	Illawarra Shoalhaven, South East Sydney

A brief profile of each of the five CMOs is provided in Table 4 that includes details of current staffing levels and associated qualification requirements.

[14] A number of 'Parramatta Mission' services, including the FCMHP, transitioned to 'Uniting' from 1 July 2021. The name 'Uniting' has therefore been used in the remainder of this report.

Table 4 Overview of FCMHP CMOs

CMO	Organisation overview	FCMHP staffing	Qualification requirements
CatholicCare Wilcannia-Forbes	CatholicCare Wilcannia-Forbes (formerly CentaCare) runs a range of services under five major programs and employs around 100 staff. It has 19 office locations, in addition to the head office located in Forbes. THE FCMHP positions are located at seven sites across the two LHDs it partners with.	FTE: 5.5 Includes a program manager and team leader (based in Bathurst and Parkes respectively), who work across both Far West and Western NSW LHDs; and support workers located at Broken Hill and Mildura (Far West LHD), and Bathurst, Dubbo and Narromine (Western NSW LHD). There is also a peer worker role based at Orange, working with Western NSW LHD.	Support workers are required to hold (or be working towards), a Diploma in Mental Health, and undertake a range of mandatory training relevant to the FCMHP as part of their employment.
Mission Australia	Mission Australia is a national organisation that was formed through the merger and amalgamation of many different organisations. In addition to addressing mental health issues, it delivers a range of services such as access to affordable housing and supporting people with disability. The FCMHP positions are located at three sites across the two LHDs it partners with.	FTE: 5.7 Includes a program manager who works across both Mid North Coast and Northern LHDs (based in Coffs Harbour), support workers at Coffs Harbour and Port Macquarie (Mid North Coast), and Lismore (Northern). There are also education and training co-ordinator roles in Coffs Harbour, Lismore and Port Macquarie.	Support workers are required to hold a two year diploma in Social Welfare (or higher), or have relevant industry experience. There are no specific FCMHP training requirements for staff.
One Door Mental Health	One Door Mental Health has more than 45 offices across NSW and employs around 270 staff. It began as the Schizophrenia Fellowship of NSW, and provides services to people who live with or care for people with mental illness. The FCMHP positions are located at 17 sites across the five LHDs it partners with.	FTE: 15.36 Includes carer advocates, who undertake the support worker role. Carer advocates are located in at least two locations for each of the LHDs they are in partnership with. There are Vietnamese identified roles working with Sydney LHD and South Western Sydney LHD (total 0.5 FTE).	Carer advocates are required to hold a Certificate IV in Mental Health or Community Services, or have relevant industry experience. There are no specific FCMHP training requirements, apart from Carers Star training.
Uniting	Uniting (the FCMHP transitioned to Uniting from	FTE: 13	Support workers are required to hold a

CMO	Organisation overview	FCMHP staffing	Qualification requirements
	1 July 2021) delivers more than 70 services across Greater Western Sydney, including meals, accommodation and mental health services, and employs around 500 staff. The FCMHP positions are located at four sites, one in each of the four LHDs it partners with.	Includes a program manager (Central Coast), team leaders (Nepean Blue Mountains, Northern Sydney, Western Sydney), and support worker and carer peer worker positions for each LHD.	Certificate IV in Mental Health (or equivalent), and carer peer workers require a Certificate IV in Peer Work (or be working towards). There are no specific FCMHP training requirements.
Stride	Stride (formerly known as Aftercare) provides mental health services in all the eastern states, and employs over 600 staff. The FCMHP positions are located at three sites across the two LHDs it partners with.	FTE: 7.2 Includes the service manager and a service leader who work across both Illawarra Shoalhaven and South East Sydney, support workers for each LHD (based in Nowra, Wollongong and South Hurstville), and a carer peer worker working with Illawarra Shoalhaven.	Support workers are required to hold a tertiary qualification in Disability Services, Mental Health, Nursing, Social Work or Psychology (desirable) or other area, or a Diploma or Certificate in a related area. All staff undertake a range of mandatory training relevant to the FCMHP as part of their employment.

LHDs and CMOs generally undertake different aspects of the FCMHP, although there is some degree of overlap. CMOs provide community based education and training, individual support and advocacy services, and planning and infrastructure support for mental health-carer support groups.

CMOs use the Carers Star and a range of other tools and assessments, such as the traffic light system, to triage individual carer needs and guide service provision. Carers may stay with a CMO for long periods of time, including as part of a support group, or access services for a shorter period of time only.

The LHDs generally employ a Program Coordinator as a minimum for the program. FCMHP coordinators may or may not provide face-to-face services to carers, or may act in a coordinating role only, depending on the approach and level of resources with each LHD. In some LHDs, additional staff may also be employed to deliver the program services. In addition to organising referrals to the CMO, LHD services can include clinical consultation and support to clinicians, specialist interventions and education about mental health issues for families and carers, and the delivery of a wide range of initiatives for mental health staff and community partners. The aim of these activities is to increase the skills and confidence of staff to work within a family and carer inclusive framework.

2.2.1 The Justice Health and Forensic Mental Health Network (JH&FMHN)

The JH&FMHN is also part of the FCMHP. The FCMHP Program Coordinator for the JH&FMHN is located within Long Bay Hospital. The program at JH&FMHN includes families and carers from across NSW and as such interacts with all CMOs through the JH&FMHN Family and Carer Consultant.

A Memorandum of Understanding (MOU) enables the Program Coordinator at Justice Health to run workshops with carers and clinicians within the Justice Health system. Individual MOUs with CMOs also facilitates individual support of carers, including face-to-face meetings. Education programs are provided to clinicians within the JH&FMHN in conjunction with carers from the custodial system and CMOs, as well as peak bodies.

2.2.2 Culturally and Linguistically Diverse (CALD) services

The CALD Care and Support Program provides specialist CALD representation for the FCMHP through the Transcultural Mental Health Centre (TMHC). This program began as a demonstration project in 2002, led by the TMHC Carer Program Coordinator, and has remained a part of the FCMHP since its inception.

The CALD Care and Support Program recruits, trains and supports small groups of bilingual group leaders across Sydney to reach out to CALD communities using the bilingual brokerage model. Currently the CALD Care and Support Program has 11 bilingual group leaders running 14 carer support groups, covering 10 languages across Sydney. The program also works with providers to help CALD carers gain access to respite. The program runs groups across five LHDs, including South Western Sydney, South Eastern Sydney, Western Sydney, Central and Northern Sydney.

2.2.3 Policy and legislative framework

It is critical for the FCMHP evaluation to consider the legislative and policy framework in which the program operates. NSW legislation explicitly recognises the important contribution that carers make to the people they care for and their need for support to continue this role. The NSW Carers Recognition Act[15] recognises that the needs of carers are diverse and should be acknowledged and recognised in service delivery.

A continuing barrier for carers has been the issue of privacy and confidentiality in relation to consumer consent and the responsibilities of clinicians in providing information to families and carers. This was resolved in 2007 when a new NSW Mental Health Act provided for 'primary carers' who, under prescribed circumstances which included properly informed consumer consent, could be given essential information from a mental health service so as to better guide the care of their loved one.[16]

Subsequent amendments in 2014 provided an increased focus on the recovery of consumers, and further clarified and strengthened the role of carers. Chapter 4 of the Mental Health Act 2007 acknowledges that families and carers and the people they support

[15] New South Wales Parliament (2010) NSW Carers (Recognition) Act 2010 No 20.
[16] New South Wales Parliament (2007) Mental Health Act 2007, Chapter 4, Part 1.

have the right to be included in planning and decisions regarding all aspects of care and treatment. Constraints upon the disclosure of confidential medical information remain within the Act and other legislation, however, the Act clearly identifies the right of carers to be involved in their loved one's care.[17]

At a national policy level, the *National Mental Health Plan 2003-2008* contained key direction statements regarding families and carers in the specific context of mental health, including that supporting carers is the responsibility of all levels of governments and the community as a whole: 'Mental health should be understood within a population health framework that takes into account the complex influences on mental health, (and) encourages a holistic approach to improving mental health and wellbeing'.[18]

The NSW Mental Health Commission was established following the creation of the Mental Health Commission Act 2012; this being the result of an exhaustive process of community consultation by the Mental Health Taskforce established for this purpose by the NSW Government. The NSW Mental Health Commission has a particular responsibility to 'engage and consult with people who have a mental illness and their families and carers,' and to utilise their lived experience in the process of reforming mental health services.[19]

At a state level, the policy underpinning the FCMHP includes a major ten-year reform agenda with a core focus of building an effective and integrated community support sector. The key policy document underpinning the expansion of the CMO-led and managed model of integrated care is the *Living Well: A Strategic Plan for Mental Health in NSW 2014 – 2024*. In this document, John Feneley, the NSW Mental Health Commissioner, states that the strategic plan provides the overarching 'directions and principles for reform which agencies and service providers must find ways to embed in the supports they offer to people in the community'. [20] More recently, the NSW Mental Health Commission released the strategic plan *Living Well in Focus 2020-2024.*[21] Among the key actions for reform are two which refer specifically to carers as a priority: Action 12 'Ensure effective inclusion of families, carers and kin in mental health and social services' and Action 13 'Continue to grow the carer peer workforce'. This document includes information about the FCMHP.

Policy statements directly relevant to the FCMHP are outlined in the following points:

The Carer Recognition Act 2010 and the NSW Carers Charter aims to increase recognition and awareness of carers and acknowledges the valuable contribution they make to society.

Chapter 4 of the Mental Health Act 2007 acknowledges that families and carers and the people they support have the right to be included in planning and decisions regarding all aspects of care and treatment.

[17] Haisman B (2018) op. cit.
[18] National Mental Health Strategy (2003) National Mental Health Plan, 2003-08, Commonwealth of Australia, Canberra, p 4.
[19] New South Wales Parliament (2012) Mental Health Commission Act 2012, No 13, Part 3.
[20] NSW Mental Health Commission (2014) *Living Well: A Strategic Plan for Mental Health in NSW*, Sydney.
[21] Mental Health Commission of NSW (2020) *Living Well in Focus: 2020-2024*.

Standard 2 of the National Safety and Quality Health Service Standards[22] includes that families and carers and the people they support have the right to contribute to the improvement of mental health services.

Standard 3 and Standard 7 of the National Standards for Mental Health Services 2010 also promotes consumer and carer participation in all aspects of care and treatment and the design and delivery of services.

2.3 Program theory underpinning the FCMHP

The National Standards for Mental Health Services, developed in 1997[23], strongly recommended involving carers and patient families in mental health care partnerships. In a paper published in 2005, Mottaghipour and Bickerton[24] found that there was no general framework for adult mental health professionals to incorporate families when working with patients with severe mental illness, in spite of its proven effectiveness in reducing patient relapse rate and family distress. Mottaghipour and Bickerton argue that the 'tasks of engaging, providing education and collaborating with families are well within the scope of an adult mental health worker'. With minimal extra training and a general framework, clinicians can incorporate family work in their everyday practice.

Services delivered by the FCMHP to carers and family are based around several tools that guide the development and delivery of the program and its activities including: the Carers Compass, the Carers Star, the Connecting With Carers DVD and Handbook, the Pyramid of Family Care and a capacity-building framework.

The Carers Compass is a central planning tool to help agencies develop their services.
The Carers Star was added in 2018 as a service delivery and outcomes tool and covers seven key areas: Health, The Caring Role, Managing at Home, Time for yourself, How you feel, Finances and Work.

The Carers Star is a version of the Outcomes Star, a suite of tools supporting and measuring change when working with people. The Carers Star was developed in a series of workshops in 2013 in the UK using an action research process.[25] The Carers Star is recommended for services that provide one-to-one ongoing support for carers and work holistically with carers. All CMOs currently use the Carers Star with their clients but they may also use it in conjunction with their own assessment. LHDs are not required to collect the Carers Star if they work with carers.

Outcome data collected from the Carers Star by CMOs using the MDS is sent to the Ministry of Health. The Carers Star is underpinned by a model of change involving five stages:

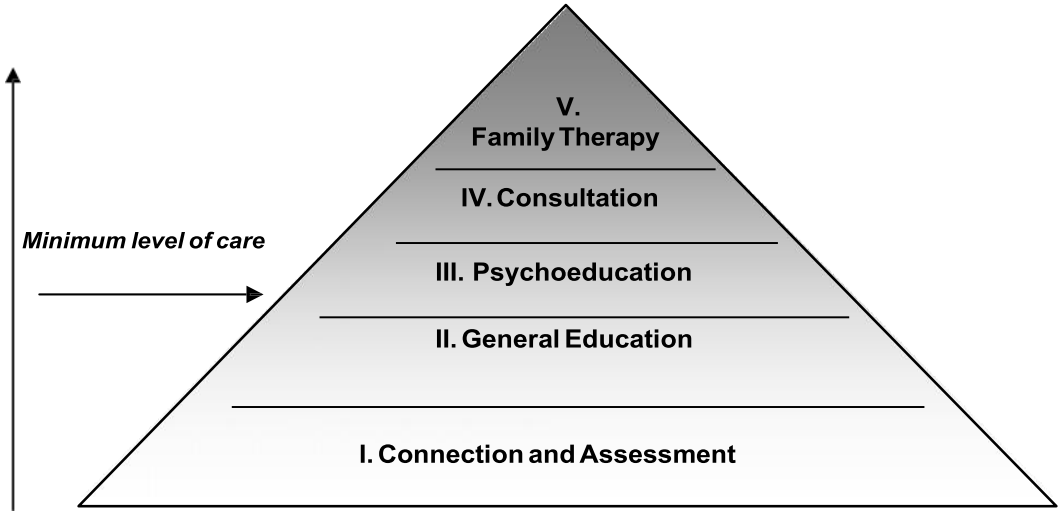
[22] Australian Commission on Safety and Quality in Health Care (2012) *National Safety and Quality Health Service Standards*, Sydney.
[23] Australian Government Department of Health (1997) *National Standards for Mental Health Services*, Canberra.
[24] Mottaghipour, Y & Bickerton, A (2005) The Pyramid of Family Care: A framework for family involvement with adult mental health services, *Australian e-Journal for the Advancement of Mental Health*, 4(3), pp. 210-217.
[25] Burns S, MacKeith J and Pearse A (2017) Carers Star: The Outcomes Star for people caring for others. Triangle Consulting Social Enterprise. UK.

1. A cause for concern: Carer is not getting support and having difficulty managing.
2. Getting help: Someone helps them understand and get the help they need.
3. Making changes: The carer takes the initiative in making changes.
4. Finding what works: Important changes have been made with support from services.
5. As good as it can be: At a stage of effective caring and getting needed support.

The main resource for the program is the *Connecting With Carers Is Everybody's Business DVD and Handbook*.[26] This handbook includes an outline of the Pyramid of Family Care, as described by Mottaghipour and Bickerton in 2005, which is used as a framework to guide family involvement (see Figure 2). The Pyramid of Family Care is based on the conceptual work of Maslow's Hierarchy of Needs that starts with the family's basic need for information up to the top level of complex needs. The underlying assumption is that basic needs must be met before higher needs. Within the Pyramid, a minimum level of care is outlined to guide the worker so that basic tasks and interventions are fulfilled before undertaking higher levels interventions for those who may need them, such as family therapy.

Levels 1 and 2 comprise the minimum level of care for all families of clients/patients. Moving on to higher levels depends on the needs of the client and their family. Each level contains a number of key tasks.

Figure 2 Pyramid of Family Care



In 2006, Mottaghipour et al[27] also discuss a capacity-building framework comprised of three components: increasing workforce knowledge and skills; increasing organisational support; and developing/ensuring appropriate resources.

[26] Bickerton, A, Hossack, K & Nair, J (Working With Families Program, Sutherland Division of Mental Health, South Eastern Sydney Illawarra Area Health Service) (2007) *Connecting with Carers Is Everybody's Business: A training resource for family friendly mental health services,* NSW Health, North Sydney.
[27] Mottaghipour Y, Woodland L, Bickerton A & Sara G (2006) Working with Families of patients within and adult mental health service: development of a programme model, *Australian Psychiatry*, 14 (3), pp. 267-271.

3 Approach to the FCMHP evaluation

In developing a methodological approach, it was important to recognise that while the program had been operating since 2005, it had not been formally evaluated. A wide range of documents were available that provided important historical context. In addition, a number of current stakeholders had been involved in the program over many years and had a deep understanding of its history. However, the theory underpinning the programs aims and objectives had not been formally documented or captured using a mechanism such as a Program Logic.

In this context, an exploratory mixed methods research design was adopted. Exploratory research is often used when information collected in an early stage of the research is likely to inform the approach used in later stages of the research.[28] For the FCMHP evaluation, this allowed the background documentation and historical knowledge of stakeholders to be thoroughly explored and inform the issues considered in the second phase of the evaluation.

Mixed methods research uses both quantitative and qualitative data to measure outcomes. Quantitative data lends itself to achieving breadth while qualitative data is typically used to achieve depth. This approach is particularly well-suited to evaluating programs such as the FCMHP, where it is being delivered across multiple organisations, as it allows the context influencing the program implementation to be understood.

The evaluation was conducted in two phases. Phase 1 comprised an initial collection and analysis of historical quantitative (administrative) and qualitative (interview) data. The findings from Phase 1 were reported to the Ministry, made publicly available and feedback sought from FCMHP stakeholders.[29]

Phase 2 of the evaluation included further quantitative (survey) and qualitative (interview) data collection activities. The approach to Phase 2 was informed by the findings of Phase 1 including the feedback received from stakeholders on the interim evaluation report. A FCMHP Evaluation Implementation Plan (submitted to the Ministry in September 2020[30]) provided a detailed outline of the scope, methodology and key issues being addressed in the evaluation.

3.1 Quantitative data collection

Four key sources of quantitative data were collected for the FCMHP evaluation as outlined in this section.

[28] Ivankova, N. V., Creswell, J. W. and Stick, S. L. (2006) 'Using Mixed-Methods Sequential Explanatory Design: From Theory to Practice', Field Methods. Sage Publications Sage CA: Thousand Oaks, CA, 18(1), pp. 3–20.
[29] Gordon R, Grootemaat P, Rahman M, Loggie C and O'Shea P (2021) Evaluation of the NSW Family and Carer Mental Health Program: Interim Report. Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong.
[30] Samsa P, Rahman M, Grootemaat P& Gordon R (2020) *Evaluation of the NSW Family and Carers Mental Health Program, Evaluation Plan*, Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong.

3.1.1 The current FCMHP Minimum Data Set (MDS)

The FCMHP MDS is collected by CMOs and submitted to InforMH on a quarterly basis. The current MDS comprises 48 variables covering carers demographic characteristics, amount of support delivered (minutes of individual, group and indirect support), and six key areas of the Carers Star outcomes tool (health, the caring role, managing at home, how you feel, time for yourself and finance). The FCMHP MDS specification is shown at Appendix 1.

FCMHP MDS data were provided for the evaluation covering the period July 2018[31] to September 2020. Data were de-identified by InforMH to align with ethical requirements. In this process, a range of variables were re-categorized or removed so that there is no potential to re-identify individuals. For example, Statistical Linkage Key (SLK) was replaced by another identifier, date of birth was replaced by age, carer code and LGBTQIA were removed, country of birth was recoded as born in/outside of Australia, preferred language was recoded as English/Not English, and suburb and postcode were replaced by Statistical Ares Level 4 (SA4). The data were transferred from InforMH to CHSD via a secure file transfer and stored securely on password protected servers. The results of the analysis of FCMHP MDS are presented in Sections 5.1 to 5.5.

3.1.2 Previous versions of the FCMHP dataset (Versions 1 to 6)

Prior to the introduction of the current FCMHP dataset in 2018, data were collected in a series of earlier datasets (referred to as FCMHP MDS Versions 1 to 6). These were routinely collected by CMOs between 2008 and 2018 through a process managed by external consultants. The data specification for the earlier versions of the FCMHP MDS is provided at Appendix 2.

The Ministry holds the data collected in FCMHP MDS Versions one to six. However, these data are less complete and generally of a much lower quality than the current FCMHP MDS. Given the quality of these historical data, it was not possible to undertake a detailed range of analyses. However, in order to provide an historical context of the carer profile of the FCMHP, the evaluation was provided with de-identified extracts from these datasets comprising:

- Registered clients and consumers' data;
- Contact and services;
- DASS assessments; and
- Support group, education/training and Information sessions data.

Again, the data were transferred from InforMH to CHSD via a secure file transfer and stored securely on password protected servers. The results of the analysis of the previous FCMHP datasets are presented in Section 5.6.

3.1.3 LHD FCMHP program dataset

LHDs are required to report FCMHP data to the Ministry on a six-monthly basis. This is included as a part of the monitoring of a suite of NSW Government Mental Health Reform

[31] The date from which the FCMHP MDS was introduced.

Initiatives. The data are reported directly to the Performance and Planning team in the Mental Health Branch.

The FCMHP reporting template was developed by a subgroup of the FCMHP steering committee and was approved by the full committee prior to implementation. Mandatory data items include:

Total staff FTE, with a breakdown of staff type and FTE of all staff employed in the program.

Activity (reported in hours), across four activity types:

- Training and Education
- Service Development
- Direct Carer Support
- Indirect Carer Support.

There is also an option on the template to report additional program information (qualitative and/or quantitative). A copy of the LHD reporting template is provided at Appendix 3.

FCMHP data were provided by the Ministry for three reporting periods from July 2019 to December 2020. Data for the most recent period of January to June 2021 were not readily available as a result of an easing of reporting requirements due to COVID 19 pandemic-related pressures on resources. The results of the analysis of the LHD dataset are presented in Section 5.7.

Prior to the implementation of the current reporting template in July 2019, a qualitative approach was used for reporting which involved LHDs providing a written summary of program activities. These reports were not in a standard format and were not used in the evaluation.

3.1.4 FCMHP Carer Experience Survey

A survey of FCMHP carers (the Carer Experience Survey) was conducted in the second phase of the evaluation. The survey was open to past or present FCMHP CMO or JH&FMHN clients. LHD clients who had accessed a FCMHP service but were not current or past clients of a CMO or the JH&FMHN were not eligible to participate in the survey. This decision was taken to maximise the homogeneity of survey respondents in terms of FCHMP services used.

The survey focussed on understanding carers' experiences around referrals to CMOs, LHDs and the JH&FMHN, barriers to participation/engagement with the program, unmet needs, overall satisfaction with the program and suggestions for improvements. A number of demographic questions were also included to gain an understanding of the profile of the survey respondents. The survey provided an important opportunity to directly explore carers' experiences of the program.

The survey instrument was piloted and changes made based on feedback. The final survey instrument comprised 24 questions (refer Appendix 4) and was available in hardcopy and through an online survey platform. CMO and JH&FMHN staff assisted with the distribution of the survey and provided assistance in its completion where required.

The survey was originally intended to be open for a six week period but was extended by two weeks due to the impact of COVID-19. The survey was therefore open from 1 July 2021 to 31 August 2021. The results of the analysis of the Carer Experience Surveys are presented in Section 5.8.

3.2 Qualitative data collection

Three key sources of qualitative data were collected for the FCMHP evaluation. Data were collected during semi-structured interviews with carers, LHDs, CMOs, specialist networks and peak bodies throughout the evaluation. In addition, the Carer Experience Survey included several open-ended questions that provided carers with an opportunity to provide feedback regarding their experience with the program.

3.2.1 Semi-structured interviews with FCMHP stakeholders

Semi-structured interviews with key FCMHP stakeholders were conducted in both phases of the evaluation. The interviews were guided by questions sent to the participants, however were semi-structured, open-ended and conversational in tone to allow for discussion on other issues that emerged.

The interview questions for the CMOs, LHDs and other stakeholders differed slightly and are shown at Appendix 5 to Appendix 7. The interviews generally took between 30-50 minutes to complete. All interviews were recorded with the permission of the interviewees. The audio files were then confidentially transcribed and uploaded into NVivo 12 Plus to facilitate data management and analysis.

Interviews were conducted with all CMOs, LHDs and the JH&FMHN, as well as peak bodies and other stakeholders. The analysis of these interviews applied a methodology known as the Framework Method. This is a well-established thematic analysis process that is particularly applicable when using data from semi-structured interviews.[32]

3.2.2 FCMHP carer interviews

Carers who completed the Carer Experience Survey were invited to express interest in participating in an interview to discuss their experiences with the FCMHP in more detail. A total of 56 carers expressed an interest in participating in an interview of which 15 were selected randomly within a sampling framework using the parameters age, gender and location (metro, regional and rural) to gain a representative sample of carers.

Carers were interviewed via Zoom videoconference by a member of the evaluation team with lived experience as a mental health carer. Carer interviews were confidentially

[32] Gale N K, Heath G, Cameron E, Rashid S & Redwood S (2013) Using the framework method for the analysis of qualitative data in multi-disciplinary health research, *BMC Medical Research Methodology*, 13 (117).

transcribed and uploaded into NVivo for analysis. Free text comments from the surveys were also extracted and entered into NVivo for analysis.

3.2.3 The FCMHP Carer Experience Survey (open-ended responses)

The Carer Experience Survey included four open-ended questions that invited respondents to provide additional comments as part of their response:

Are you planning to continue to be involved with the Family and Carer Mental Health Program? Please comment on your response.

(How) has the COVID-19 pandemic changed how you interact with or view the Program?

What do you like most about the Family and Carer Mental Health Program?

What could be improved about the Family and Carer Mental Health Program?

The vast majority of completed surveys included a response to at least one of the four open-ended questions. These responses were analysed simultaneously with the responses to the carer interviews described in the previous section.

3.3 Ethics

Ethical approval for the evaluation was granted by the University of Wollongong and Illawarra Shoalhaven Local Health District, Human Research Ethics Committee on 25 September 2020, and amendments on 19 May 2021 (2020/ETH02206).

4 Development of a program logic for the FCMHP

A program logic is often developed in the early stage of program planning as a useful tool to demonstrate how the various inputs and activities will achieve the desired outcomes. It provides a clear summary of the different elements of the program and how they fit together, demonstrating the 'theory of change'. This representative model of how the program is intended to work can then be used in the more detailed program development and as an ongoing reference for program management.

Program logic is also a useful resource in the planning and completion of evaluations. The relationship between the different program elements are clearly articulated and the aspects that are most important in achieving the intended program outcomes can be identified.

The FCMHP has not previously had a program logic in place, and it was agreed that a model would be developed as part of the evaluation. Undertaking the retrofitting of the program logic provided an opportunity to reflect on the evolution of the program and consider its operation in the current and future environmental context.[33] A draft program logic was developed using information collected in Phase 1 of the evaluation, as well as the FCMHP framework document from 2017.[34] The draft was included in the FCMHP evaluation interim report.[35]

Program logic development is an iterative process involving input from relevant stakeholders, and a period of consultation was undertaken following the publication of the interim report. The draft model was presented at the FCMHP Statewide Network meeting and was followed by further communications with members. Feedback on key elements of the draft as well as any general comments were received and were used to inform the development process through to the final version, which is presented in Figure 3.

The particular design of the model was selected as it is well suited to the retrospective development of a program logic for a mature program. The logic flows from the 'foundation' level at the bottom, up to the overarching 'purpose' level at the top, representing the way in which each of the elements underpins the one above. The 'external factors' are shown alongside to indicate that these environmental variables can potentially influence each level of the program and impact the outcomes.

The 'activities' included in the program logic are unchanged from the 2017 FCMHP framework. Some of the 'outcomes' have also come directly from the framework or have been adapted from this source. Additional outcomes have been included to more appropriately reflect the scope of the program at the family and carer, provider, and system

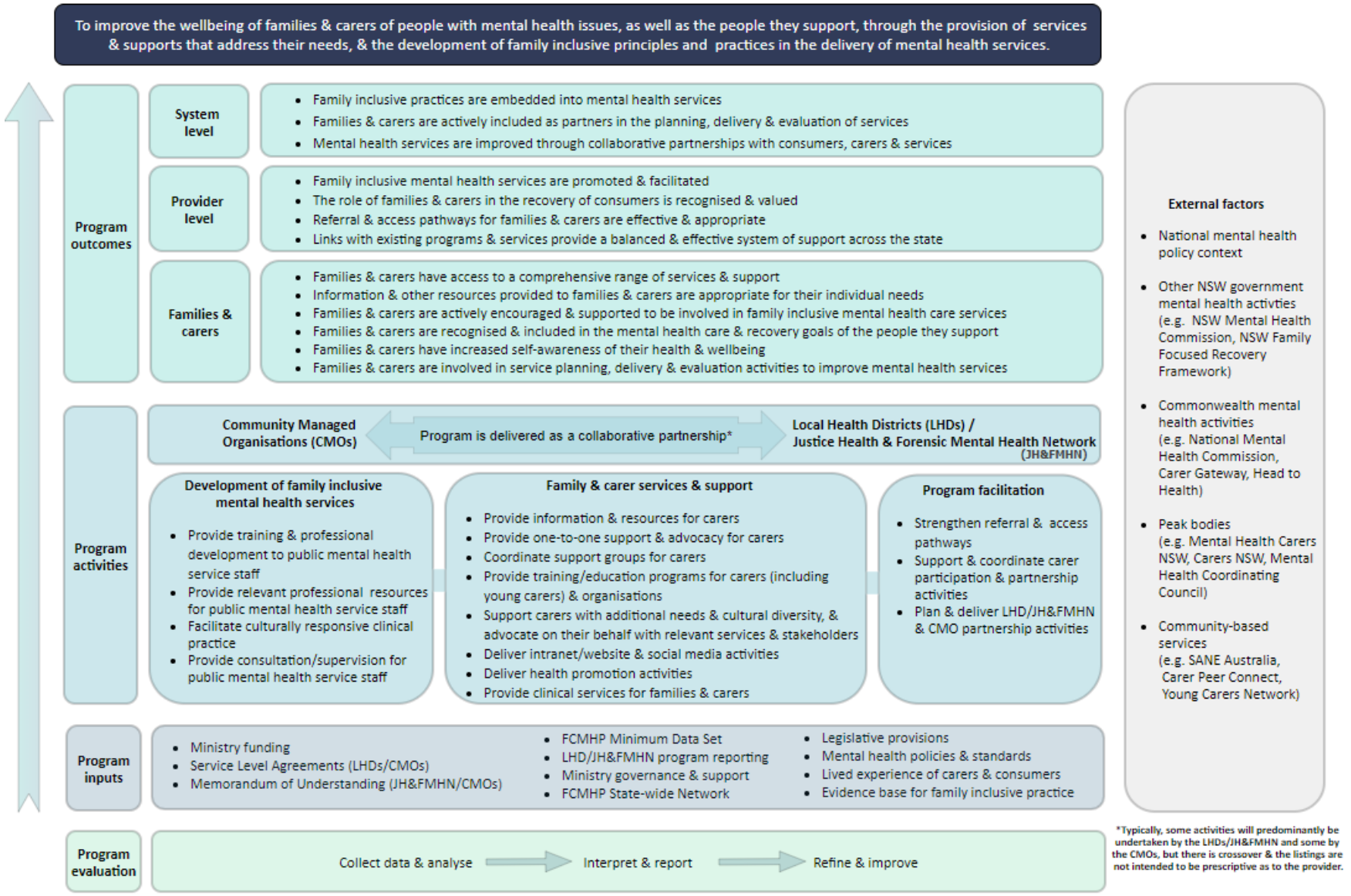
[33] National Centre for Sustainability. Evaluation Toolbox: Program Logic. Swinburne University of Technology. Available online: www.evaluationtoolbox.net.au.
[34] NSW Family and Carer Mental Health Program framework. Available online: www.health.nsw.gov.au/mentalhealth/services/carers/Pages/support-framework.aspx.
[35] Gordon R, Grootemaat P, Rahman M, Loggie C and O'Shea P (2021) Evaluation of the NSW Family and Carer Mental Health Program: Interim Report. Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong.

levels. The overall program purpose at the top of the model is modified from the 2017 framework.

The program logic highlights the partnership approach between LHDs and the CMOs, which is a critical feature of the program. It should be noted, that while the activities have been listed under three separate categories, this does not reflect any division of the activities between LHDs and CMOs. Rather, they are grouped according to the participants that will take part in the activities. Delivery of the FCMHP is intended to be flexible, with providers able to tailor the different elements of the program according to local needs and circumstances. As such, there is variation across the state regarding which activities are undertaken by different providers. Further, many program activities are to be undertaken in partnership.

It is hoped that the FCMHP program logic provides a valuable resource for providers, the Ministry and other key stakeholders. It is important that the model is reviewed regularly and updated as required to ensure that it accurately reflects the intended purpose and outcomes of the program and the different elements that contribute to the process of change.

Figure 3 Family and Carers Mental Health Program - Program Logic



5 Results: Quantitative data

A significant volume of quantitative data were collected and analysed for the FCMHP evaluation. This included both routinely collected administrative data provided by the Ministry and survey data collected by the evaluation team. The methodology underpinning the data collection was outlined in Section 3. This section presents the results of a series of analyses across these datasets.

In conducting this analysis, an important objective was to quantify and delineate historical FCMHP activity. Given that the FCMHP has not previously been evaluated, providing a descriptive profile of historical activity was in itself an important output of the evaluation.

In addition, this analysis aimed to develop a more sophisticated understanding of patterns of service utilisation. In particular, the analyses have explored associations between carers' characteristics and the levels and types of support services received, and assessed the relative importance of the different types of services offered by the FCMHP.

Within this framework, this Section presents the results of four separate sets of data analyses:

- Sections 5.1 to 5.5 presents an analysis of the FCMHP MDS for the period July 2018 [36] to September 2020;
- Section 5.6 presents an analysis of historical data pre-dating the introduction of the FCMHP MDS for the period 2008 to 2018;
- Section 5.7 presents an analysis of LHD FCMHP data for the period from July 2019 to December 2020;
- Section 5.8 presents the results of the FCMHP Carer Experience Survey conducted between July 2021 and August 2021.

The results included in the interim report have been re-presented in this report to provide a consolidated set of evaluation findings. However, the results have been expanded to reflect additional analyses conducted since the interim report was finalised. Specifically, the results presented in Section 5.3.2, 5.3.4, 5.3.6 and 5.4 represent new analyses of FCMHP MDS data that was not included in the interim report. Similarly, the results presented in Sections 5.7 and 5.8 present analyses of new data collections associated with FCMHP LHD data collection and the Carer Experience Survey undertaken since the interim report.

5.1 The FCMHP Minimum Data Set

An outline of the FCMHP MDS was provided in Section 3.1.1. As noted, it is collected by CMOs and submitted to InforMH on a quarterly basis. The current MDS comprises 48 variables covering carers' demographic characteristics, amount of support delivered (minutes of individual, group and indirect support), and six key areas of the Carers Star outcomes tool (health, the caring role, managing at home, how you feel, time for yourself and finance). The FCMHP MDS specification is shown at Appendix 1.

[36] The date on which the FCMHP MDS was introduced.

Data provided for the evaluation were de-identified by InforMH to align with ethical requirements. In this process, a range of variables were re-categorized or removed so that there is no potential to re-identify individuals. For example, Statistical Linkage Key (SLK) was replaced by another identifier, date of birth was replaced by age, carer code and LGBTQIA were removed, country of birth was recoded as born in/outside of Australia, preferred language was recoded as English/Not English, and suburb and postcode were replaced by SA4. The data were transferred from InforMH to the CHSD data server via a secure file transfer and are stored securely on password protected servers.

The evaluation received 16,540 data items/observations for 6,201 distinct carers who were supported by the five CMOs (Stride, Catholic Care, Mission Australia, One Door Mental Health, and Uniting) across different LHDs between July 2018 and September 2020.

The following analyses have been completed:

- Demographic and referral source characteristics of carers by CMO (Section 5.2);
- Median support time and interquartile range (IQR) [37] individual, group, and indirect support for each CMO (Section 5.3);
- A longitudinal analysis of outcomes based on the Carers Star outcomes tool (Section 5.4).

5.2 Demographic characteristics

Table 5 shows the demographic and referral source characteristics of carers who received support. The most common age group of carers was 50-59 across all CMOs except Catholic Care (40-49) where a higher proportion of carers aged less than 20 and over 80 were reported. Interestingly, almost 80% of carers across all CMOs were female. Around 14% of carers at Catholic Care (which services most remote areas of NSW) were from an Indigenous background while this proportion at the other CMOs was less than 6%. There was a wide variation in the sources of referral across CMOs, with two most common sources being 'Self' and 'Public Mental Health Service referral'.

While most of the carers (90%) at Catholic Care visited other community care services, the proportion was relatively low at other CMOs (Mission Australia: 43%, One Door Mental Health: 26%, and Stride: 26%), with carers in Uniting having no records of other community visits. Most of the carers at Catholic Care completed Carers Star chart (88%) followed by Uniting (77%), One Door Mental Health (74%), Stride (60)%, and Mission Australia (41%).

[37] The interquartile range (IQR) is the range of the middle half of the dataset.

Table 5 Carers demographic and service characteristics (Jul 2018 to Sep 2020)

Characteristic	Stride (n=990) %	Catholic Care W-F (n=475) %	Mission Australia (n=475) %	One Door MH(n=3,128) %	Uniting (n=1,133) %	Total (n=6,201) %
Demographic						
Age						
<20	0.8	6.7	0.2	2.2	0.9	1.9
20-29	2.5	3.6	1.1	4.4	2.4	3.4
30-39	7.8	10.7	5.7	9.6	6.4	8.5
40-49	16.7	22.5	13.1	20.4	15.4	18.5
50-59	34.3	21.5	26.5	26.2	35.8	28.9
60-69	22.6	15.0	31.6	22.0	24.6	22.8
70-80	12.2	15.0	18.1	12.5	12.4	13.1
≥80	3.0	5.1	3.8	2.6	2.1	2.9
Sex						
Male	18.4	20.0	18.7	21.1	24.7	21.1
Female	81.6	80.0	81.3	78.7	75.2	78.8
Country of birth						
Australia	80.8	96.0	82.1	76.5	72.2	78.3
Outside Australia	19.2	4.0	17.9	23.5	27.8	21.7
Indigenous status						
Indigenous	4.2	14.0	3.2	5.7	2.5	5.3
Non-Indigenous	95.9	86.1	96.9	94.3	97.5	94.7
Language speaking at home						
English	86.4	98.3	95.4	80.7	81.1	84.1
Not English	13.6	1.7	4.6	19.3	18.9	15.9
Interpreter required						
Yes	0.2	0	0.2	3	0	1.3
No	99.8	100.0	99.8	97.5	100.0	98.7
Referral source						
Self	24.1	31.2	34.3	24.1	60.6	32.1
Family or Friend	9.2	5.7	10.1	4.4	2.8	5.4
Public Mental Health Service	54.7	34.7	22.1	46.0	15.5	39.1
Public Health Service	2.6	10.7	5.9	1.5	4.6	3.3
General practitioner	0.4	0.0	0.2	0.1	0.2	0.2
Other Private Health Service	3.0	0.0	2.1	0.8	0.4	1.1
CMO (Different Provider)	4.0	9.5	16.6	10.2	12.4	10.1
CMO (Same Provider)	1.9	5.9	2.3	0.8	1.7	1.6
Other	0.0	1.3	5.3	5.7	1.9	3.7

Characteristic	Stride (n=990) %	Catholic Care W-F (n=475) %	Mission Australia (n=475) %	One Door MH(n=3,128) %	Uniting (n=1,133) %	Total (n=6,201) %
Unknown/not stated	0.0	1.1	1.1	6.5	0.0	3.5
Referral to other services						
Yes	40.6	28.8	45.1	54.1	17.4	42.6
No	59.4	71.2	55.0	45.9	82.6	57.4
Visit Community Services						
Yes	25.7	89.5	42.7	26.1	0	27.4
No	74.3	10.6	57.3	73.9	100.0	72.6
Carers Star Chart completed						
Yes	59.5	87.8	40.6	73.7	76.6	70.5
No	40.5	12.2	59.4	26.3	23.4	29.5

5.3 Level of support provided

The FCMHP MDS captures detailed data on the number of minutes of support provided by service providers in three broad categories: individual support, group support, and indirect support. The breakdown of time reported against each category by CMO is presented below.

5.3.1 Individual support

Individual support captures direct time spent with carers and is recorded as 'information', 'advocacy', 'emotional support', 'education and training', and 'referral' activities. The number of carers receiving this support and the number of minutes reported against each category is shown in Table 6.

'Information' was the most frequently reported category in terms of the number of clients receiving this service (85%), although there was considerable variation between CMOs (21% to 98%). Emotional support was the second most commonly reported service based on number of clients with 79% of carers across all the CMOs recording this type of support.

The 'emotional support' category had the largest the number of reported minutes across CMOs (median: 96 minutes, IQR: 45-223). Carers at Uniting received the highest amount of emotional support time (median: 238 minutes, IQR: 93-595), while carers at One Door Mental Health received the lowest for this category (median: 75 minutes, IQR: 40-150).

Almost 25% of carers received 'advocacy' services but again with substantial variation between CMOs (ranging from 12% at Uniting to 32% at One Door Mental Health). The overall median advocacy support time was 42 minutes (IQR: 20-90) with Catholic Care providing the highest median time 50 minutes (IQR: 20-120) and Stride providing the lowest median time 32 minutes (IQR: 15-72).

Overall, 20% of carers received 'education and training' support, but this also varied widely by CMO ranging from only 1% at Mission Australia to 27% at One Door Mental Health. The

median time spent on education and training was almost 30 minutes (IQR: 15-34) across CMOs. Catholic Care provided the largest number of minutes on this support activity (median: 120 minutes, IQR: 20-420).

Finally, almost 40% of carers received 'referral' support, with median of 25 minutes (IQR: 15-45). Nearly half the carers (49%) at Stride received support on referral service, followed by Uniting (42%), and One Door Mental Health (41%). While a substantial proportion of carers (40%) at Catholic Care received travel support, there were very few carers at the other CMOs that received this service.

Table 6 Minutes of individual support (Jul 2018 to Sep 2020)

Types of support	Stride (n=990)	Catholic Care W-F (n=475)	Mission Australia (n=475)	One Door MH (n=3,128)	Uniting (n=1,133)	Total (n=6,201)
Information						
n (%)	954 (96%)	435 (92%)	99 (21%)	2,262 (72%)	1,109 (98%)	5,259 (85%)
Median (IQR)	63 (30-134)	75 (30-138)	40 (20-70)	60 (30-124)	209 (82-477)	80 (34-183)
Advocacy						
n (%)	161 (16%)	117 (25%)	100 (21%)	987 (32%)	131 (12%)	1,496 (24%)
Median (IQR)	32 (15-72)	50 (20-120)	33 (30-60)	45 (20-95)	37 (15-90)	42 (20-90)
Emotional						
n (%)	834 (84%)	347 (73%)	378 (80%)	2,484 (79%)	873 (77%)	4,916 (79%)
Median (IQR)	81 (33-164)	140 (65-375)	135 (65-285)	75 (40-150)	238 (93-595)	96 (45-223)
Education and training						
n (%)	228 (23%)	68 (14%)	6 (1%)	833 (27%)	127 (11%)	1,262 (20%)
Median (IQR)	28 (14-60)	120 (20-420)	30 (15-40)	30 (15-79)	22 (15-45)	30 (15-74)
Referral						
n (%)	486 (49%)	136 (29%)	54 (11%)	1,284 (41%)	477 (42%)	2,437 (39%)
Median (IQR)	21 (12-36)	40 (20-105)	30 (15-30)	25 (15-45)	30 (15-52)	25 (15-45)
Travel						
n (%)	66 (1%)	192 (40%)	11 (2%)	-	4 (0.3%)	273 (4%)
Median (IQR)	47 (33-138)	90 (38-250)	30 (20-60)	-	118 (54-154)	80 (30-177)

5.3.2 Individual support by metropolitan and regional LHD

Table 7 presents the proportion of carers and the median number of minutes of individual support received in metropolitan and regional LHDs between July 2018 and September 2020. It shows that carers in metropolitan LHDs received statistically significantly more minutes of support than carers in regional LHDs two of the three most frequently used services -

'information support' (90 minutes vs 75 minutes; p<0.001) and 'emotional support' (104 minutes vs 90 minutes; p<0.001). The issue of service access in remote locations is discussed further in Section 6.2.

This is an important finding that contributes to a statistically significantly greater number of total minutes of support being received by carers in metropolitan LHDs versus regional LHDs (194 minutes vs 168 minutes; p<0.001). There was no statistically significant difference between metropolitan and regional LHDs in the number of minutes of support across the other types of individual support.

Table 7 Individual support: metropolitan vs regional LHDs (July 2018 to September 2020)

Support type	Total (n=6,201)	Metropolitan LHDs (n=3,190)	Regional LDDs (n=3,011)	p-value
Information				
n (%)	5,259 (85%)	2,876 (90%)	2,435 (81%)	
Median minutes (IQR)	80 (34-183)	90 (32-224)	75 (35-150)	(p<0.001)*
Advocacy				
n (%)	1,496 (24%)	698 (22%)	798 (27%)	
Median minutes (IQR)	42 (20-90)	40 (19-95)	45 (20-90)	(p=0.114)
Emotional				
n (%)	4,916 (79%)	2,507 (79%)	2,409 (80%)	
Median minutes (IQR)	96 (45-223)	104 (47-250)	90 (45-194)	(p<0.001)*
Education & training				
n (%)	1,262 (20%)	635 (20%)	627 (21%)	
Median minutes (IQR)	30 (15-74)	30 (15-79)	29 (15-70)	(p=0.076)
Referral				
n (%)	2,437 (39%)	1,292 (41%)	1,145 (38%)	
Median minutes (IQR)	25 (15-45)	24 (15-45)	25 (15-45)	(p=0.080)
Travel				
n (%)	273 (4%)	70 (<1%)	203 (7%)	
Median minutes (IQR)	80 (30-177)	53 (33-138)	90 (30-240)	(p=0.019)*
Total				
n (%)	**5,988 (97%)**	**3,102 (97%)**	**2,886 (96%)**	
Median minutes (IQR)	**180 (85-413)**	**195 (75-480)**	**168 (90-355)**	**(p<0.001)***

* Statistically significant result based on Wilcoxon Rank-Sum test (p<0.05).

5.3.3 Group support

Group support captures time spent with carers who attend 'information sessions', 'education/training courses' and 'support groups'. Time reported against each category by CMO is shown in Table 8. A substantial proportion of carers at Catholic Care (32%) and Uniting (39%) had 'information' reported on a group basis, with median number of minutes reported as 90 (IQR: 10-240) and 105 (IQR: 45-300) respectively. In contrast, a much lower proportion of carers at One Door Mental Health (5%), Mission Australian (9%) and Stride (13%) had this activity category recorded.

Over 50% of carers at Mission Australia received education and training in a group situation, compared with 33% at Uniting, 27% at Catholic Care, 24% at One Door Mental Health and 22% at Stride. The median number of minutes was notably high ranging from 240 minutes (IQR: 180-540) at Catholic Care to 420 minutes (IQR: 312-904) at Uniting.

About 25% of carers participated in support groups again with substantial variations between the CMOs. The highest proportion of carers was at Mission Australia (39%) with median support time 415 minutes (IQR: 145-840). In contrast, only 17% of the carers at One Door Mental Health participated in support groups with median support time 240 minutes (IQR: 120-521).

Table 8 Minutes of group support (Jul 2018 to Sep 2020)

Types of support	Stride (n=990)	Catholic Care W-F (n=475)	Mission Australia (n=475)	One Door MH (n=3,128)	Uniting (n=1,133)	Total (n=6,201)
Information						
n (%)	133 (13%)	150 (32%)	41 (9%)	142 (5%)	441 (39%)	907 (15%)
Median	168	90	240	120	105	120
(IQR)	(36-435)	(10-240)	(180-330)	(60-210)	(45-300)	(45-307)
Education and training						
n (%)	222 (22%)	127 (27%)	255 (54%)	737 (24%)	371 (33%)	1,712 (28%)
Median	420	240	440	240	390	360
(IQR)	(312-904)	(120-605)	(180-840)	(180-540)	(240-930)	(180-720)
Support group						
n (%)	271 (27%)	140 (29%)	184 (39%)	524 (17%)	413 (36%)	1,532 (25%)
Median	418	380	415	240	247	299
(IQR)	(158-1,320)	(140-699)	(145-840)	(120-521)	(120-660)	(135-710)

5.3.4 Group support by metro and regional LHD

Table 9 presents the proportion of carers and the median number of minutes of group support received in metropolitan and regional LHDs between July 2018 and September 2020. Unlike individual support, a noticeably smaller proportion of carers (metro LHD: 18% vs regional LHD: 11%) received group 'information support'. However, a substantial proportion of carers did receive 'support' (29% vs 20%) and 'education and training' (28%) in a group setting across both metropolitan and regional LHDs.

Overall, a noticeably higher proportion of carers in metropolitan LHDs received at least one type of group support (47% vs 36%), with the median length of support time being 405 minutes compared with 360 minutes. However, this difference in overall levels of group support services received was not statistically significant.

Table 9 Group support metro and regional LHD- July 2018 to September 2020

Support type	Total (n=6,201)	Metro LHDs (n=3,190)	Regional LHDs (n=3,011)	p-value
Information				
n (%)	907 (15%)	577 (18%)	330 (11%)	
Median minutes (IQR)	120 (45-307)	120 (45-345)	120 (60-240)	(p=0.040)*
Education and training				
n (%)	1,712 (28%)	880 (28%)	832 (28%)	
Median minutes (IQR)	360 (180-720)	360 (180-810)	300 (180-635)	(p=0.002)*
Support group				
n (%)	1,532 (25%)	933 (29%)	599 (20%)	
Median minutes (IQR)	299 (135-710)	300 (149-780)	270 (120-620)	(p=0.003)*
Total				
n (%)	**2,597 (42%)**	**1,495 (47%)**	**1,102 (36%)**	
Median minutes (IQR)	**380 (180-935)**	**405 (165-968)**	**360 (180-870)**	**(p=0.081)**

* Statistically significant result based on Wilcoxon Rank-Sum test (p<0.05).

5.3.5 Indirect support

Indirect support captures time spent on carer administration (e.g. making bookings or spending time to research service options) and time spent on travel to and from a carer to provide support. Time reported against each category by CMO is shown in Table 10. Most carers at One Door Mental Health (95%) and Stride (89%) had time recorded against this activity with a median of 60 minutes (IQR: 30-120) and 73 minutes (IQR: 27-225), respectively. Almost half of the carers at Uniting had time recorded against this activity, with the highest median of 193 minutes (IQR: 90-405).

The lowest proportion of carers (31%) with time recorded against carer administration was at Catholic Care, with median support time of 45 minutes (IQR: 20-95). 'Time to and from carer' was recorded for almost one third of carers, with substantial variations between CMOs (ranging from 25% at One Door Mental Health to 45% at Uniting). The highest median support time was recorded at Catholic Care (180 minutes with IQR: 30-380) followed by Uniting (145 minutes with IQR: 60-350), Mission Australia (120 minutes with IQR: 60-297) and Stride (90 minutes with IQR: 38-229).

Table 10 Minutes of indirect support (Jul 2018 to Sep 2020)

Types of support	Stride (n=990)	Catholic Care W-F(n=475)	Mission Australia (n=475)	One Door MH (n=3,128)	Uniting (n=1,133)	Total (n=6,201)
Program admin						
n (%)	878 (89%)	147 (31%)	217 (46%)	2972 (95%)	571 (50%)	4,785 (77%)
Median	73	45	50	60	193	65
(IQR)	(27-225)	(20-95)	(30-110)	(30-120)	(90-405)	(30-150)
Travel to and from carer						
n (%)	436 (44%)	147 (31%)	152 (32%)	780 (25%)	515 (45%)	2,030 (33%)
Median	90	180	120	40	145	75
(IQR)	(38-229)	(30-380)	(60-297)	(20-75)	(60-350)	(30-195)

5.3.6 Indirect support by metro and regional LHD

Table 11 presents the proportion of carers and the median number of minutes of indirect support received in metropolitan and regional LHDs between July 2018 and September 2020. Over three quarters of carers (77%) received 'program admin support, with a statistically significant higher average length of support time in metropolitan versus regional LHDs (75 minutes vs 60 minutes).

Unlike individual travel support, a substantially higher proportion of carers in metropolitan compared with regional LHDs (40% vs 26%) received indirect travel support (travel to and from carer). Further, a statistically significantly higher average length of support time (90 minutes vs 60 minutes; p<0.001) was received.

Table 11 Indirect support metro and regional LHD- July 2018 to September 2020

Support type	Total (n=6,201)	Metro LHDs (n=3,190	Regional LHDs (n=3,011)	p-value
Program admin				
n (%)	4,785 (77%)	2,453 (77%)	2,332 (77%)	
Median minutes	65	75	60	(p<0.001)*
(IQR)	(30-150)	(30-195)	(15-120)	
Travel to and from carer				
n (%)	2,030 (33%)	1,262 (40%)	768 (26%)	
Median minutes	75	90	60	(p<0.001)*
(IQR)	(30-195)	(36-210)	(25-150)	
Total				
n (%)	**5,029 (81%)**	**2,555 (80%)**	**2,474 (82%)**	
Median minutes	**81**	**98**	**70**	**(p<0.001)***
(IQR)	**(30-210)**	**(35-290)**	**(30-165)**	

* Statistically significant result based on Wilcoxon Rank-Sum test (p<0.05).

5.4 Predictors for the amount of support received

The levels of individual, group and indirect support services reported in the previous sections were further analysed to examine associations between sociodemographic characteristics and levels of support services received. Multivariate linear regression was used for this analysis.

Table 12 presents the regression outputs for the prediction of the amount of support received by the carers between July 2018 and September 2020. Given the skewed distribution of levels support received, the regression model was performed after log-transformation, where the exponentiated coefficient >1 represents percentage of increase and conversely <1 represents percentage of decrease in the expected average amount of support time.

Being a younger carer (age <40) compared with carers aged 40-64 was statistically significantly associated with receiving less support (29% less individual support, 40% less group support, 38% less indirect support and 33% less overall support). In contrast, older carers (age ≥65) received statistically significantly higher levels of support than those aged 40-64 (20% more overall total support).

Female carers received statistically significantly higher levels of individual support (21%) and indirect support (22%) than male carers. However, sex was not a significant predictor of levels of group support or overall total support.

Carers' country of birth was not a significant predictor of receiving any type of support except for the indirect support. Being an overseas born carer was associated with receiving 15% less indirect support ($p<0.05$). Residing in a regional LHD was statistically significantly associated with receiving lower levels of support. Compared with carers in metropolitan LHDs, regional carers received 23% less individual support, 14% less group support, 53% less indirect support, and 31% less overall support.

Table 12 Predictors of support/care received between July 2018 and September 2020

Characteristics	Individual support Estimate (95% CI)	Group support Estimate (95% CI)	Indirect support Estimate (95% CI)	Total support Estimate (95% CI)
Age group				
Less than 40 vs 40 - 64	-29% (-42% - -13%)**	-40% (-50% - -27%)**	-38% (-49% - -24%)**	-33% (-42% - -23%)**
65 and over vs 40 - 64	+4% (-8% - +18%)	+43% (+28% - +61%)**	+16% (+2% - +31%)*	+20% (+10% - +31%)**
Sex				
Female vs male	+21% (+5% - +40%)*	±0% (-13% - +13%)	+22% (+5% - +41%)*	+10% (-1% - +22%)
Country of birth				
Born overseas vs in Australia	+9% (-4% - +25%)	-2% (-13% - +12%)	-15% (-25% - -2%)*	-2% (-12% - +7%)
Place of residence				
Regional LHDs vs Metro LHDs	-23% (-32% - -13%)**	-14% (-23% - -3%)*	-53% (-58% - -47%)**	-31% (-36% - -24%)**

**indicates significant at $p<0.001$ and * indicates significant at $p<0.05$

5.5 Carers Star outcome

The Carers Star outcome tool is used to measure and summarise changes made by people with differential care needs while working directly with them. It comprises seven domains: 'Health', 'The caring role', 'Managing at home', 'Time for yourself, 'How you feel', 'Finances' and 'Work' (data on 'Work' were not collected under the FCMHP MDS v1.0 to 1.3). Each domain measures changes on a five point scale: 'cause of concern', 'getting help', 'no pressing concern', 'mostly OK', and 'as good as it can be'. Details of the items in the Carers Star outcome tools are provided in Appendix 1.

5.5.1 Carers Star Outcomes by carers' characteristics

Table 13 presents the proportion of carers reporting better outcome ('Mostly OK' or 'Good as it can be') across six domains of the Carers Star by carer characteristics. A higher proportion of older carers (age ≥65) reported better outcome across all domains of the Carers Star (except for Health) than other age groups. For example, 49% of older carers reported 'Mostly OK' or 'Good as it can be' in the 'The Caring Role' domain compared to 39% of carers in other age groups.

Male carers were likely to report moderately better outcome than female carers across all domains of the Carers Star; for example, 62% vs 52% in 'Health' and 55% vs 45% in 'Time for yourself'. However, this result may reflect the overall smaller number of male carers. In terms of carers' country of birth, there was no noticeable difference observed in any domain of the Carers Star outcome.

Compared to non-Indigenous carers, Indigenous carer reported better Carers Star outcome in the three domains, with the proportion of 'mostly OK' or 'good as it can be' in 'Health' 59% vs 54%; 'The caring Role': 48% vs 42%; and 'How do you feel' 43% vs 39%.

Carers living in the metropolitan LHDs reported moderately better overall outcomes in Carers Star than those in regional LHDs. For example, the proportion of carers reporting 'mostly OK' or 'good as it can be' in 'Health': 56% vs 53%; 'The caring Role': 44% vs 39%; and 'Managing at home': 61% vs 56%.

Furthermore, the proportion of carers reporting better outcomes varied across the six different domains. The majority of carers reported better outcome in the three domains: namely, 'Health', 'Managing at home' and 'Finance'. In contrast, around two-fifths of carers reported 'mostly OK' or 'good as it can be' in 'The caring Role' and 'How do you feel'.

Table 13 Carers Star outcome by carer characteristics-July 2018 to September 2020

Carers' characteristics	n=4,371* (%)	% of carers reporting 'Mostly OK' or 'Good as it Can be'					
		Health	The Caring Role	Managing at Home	Time for yourself	How do you feel	Finance
Age group							
Less than 40	581 (13)	61%	39%	54%	44%	39%	60%
40-64	2,589 (59)	52%	39%	56%	41%	35%	62%
65 and over	1,201 (28)	57%	49%	66%	61%	47%	79%

Carers' characteristics	n=4,371* (%)	% of carers reporting 'Mostly OK' or 'Good as it Can be'					
		Health	The Caring Role	Managing at Home	Time for yourself	How do you feel	Finance
Sex							
Male	892 (20)	62%	44%	62%	55%	43%	67%
Female	3,474 (80)	52%	41%	58%	45%	37%	66%
Country of birth							
Born Australia	3,362 (77)	54%	42%	59%	47%	39%	67%
Born overseas	1,009 (23)	55%	41%	59%	46%	36%	65%
Indigenous status							
Indigenous	198 (5)	59%	48%	60%	48%	43%	66%
Non-Indigenous	4,013 (95)	54%	42%	59%	47%	39%	66%
Place of living							
Metro LHD	2,199 (50)	56%	44%	61%	48%	39%	68%
Regional LHD	2,172 (50)	53%	39%	56%	46%	38%	65%

*Excluding the carers who did not completed Carers Star. Around 29% (n=1830) carers did not complete Carers Star.

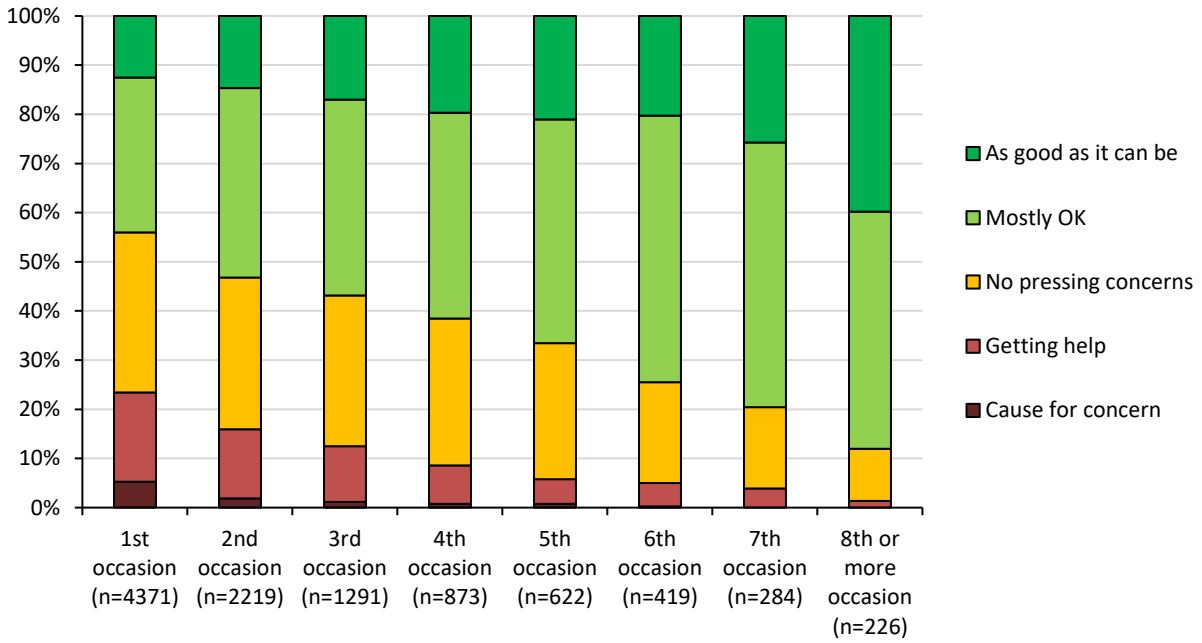
5.5.2 Longitudinal analysis of Carers Star outcomes

Almost 71% (n=4,371) of carers for whom data were available (n=6,201) completed the tool at least once between July 2018 and September 2020. A substantial proportion of carers completed the Carers Star more than once, with 36% (n=2,219) two or more times, 20% (n=1,291) three or more times, 14% (n=873) four or more times and 10% (n=622) five or more times. A longitudinal analysis of the tool is presented below for the six domains where data were available.

5.5.2.1 Carers Star: 'Health' domain

Figure 4 shows changes in scores for the Carers Star 'Health' domain across eight (or more) time points between July 2018 and October 2020. A clear trend is evident with an increasing proportion of carers reporting either 'as good as it can be' or 'mostly OK' over the period. At the first time point, 43% of carers reported one of these two responses. This increased to nearly 90% by the last time point. There was a corresponding decrease in the proportion of carers reporting either 'cause for concern' or 'getting help' over this period. The proportion of carers reporting one of these two responses decreased from 25% at the first time point to about 1% by the last time point.

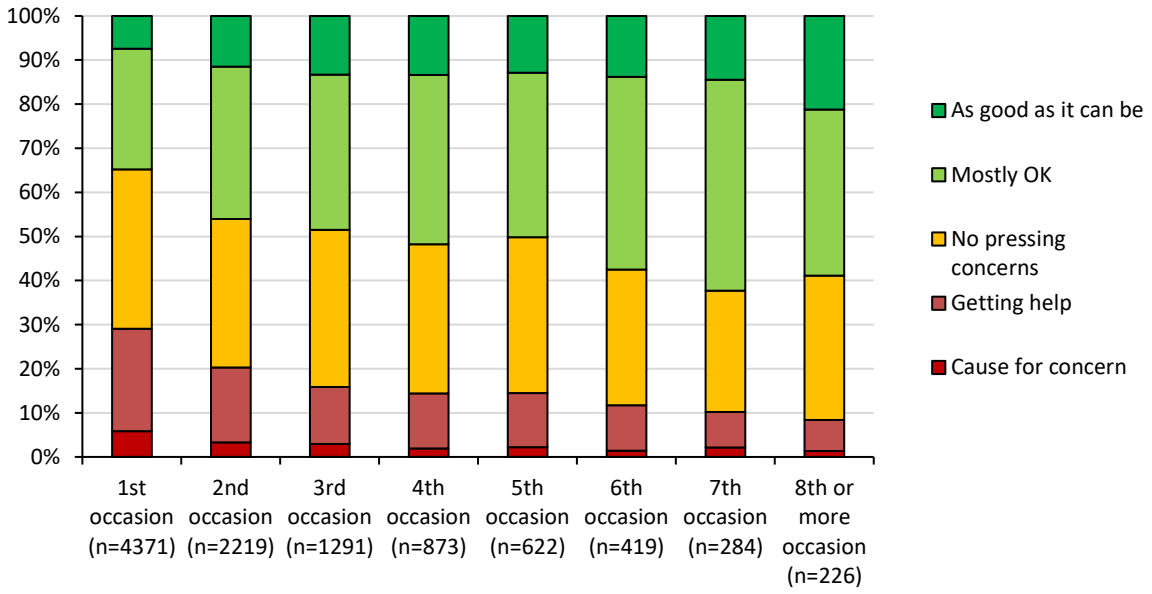
Figure 4 Changes in Carers Star 'Health' domain (Jul 2018 to Sep 2020)



5.5.2.2 Carers Star: 'The caring role' domain

Figure 5 shows changes in scores for the Carers Star 'The caring role' domain across eight (or more) time points between July 2018 and October 2020. Again, there is a clear trend with an increasing proportion of carers reporting either 'as good as it can be' or 'mostly OK' over the period. At the first time point, 35% of carers reported one of these two responses. This increased to 60% by the last time point. There was a corresponding decrease in the proportion of carers reporting either 'cause for concern' or 'getting help' over this period. The proportion of carers reporting one of these two responses decreased from 30% at the first time point to less than 10% by the last time point.

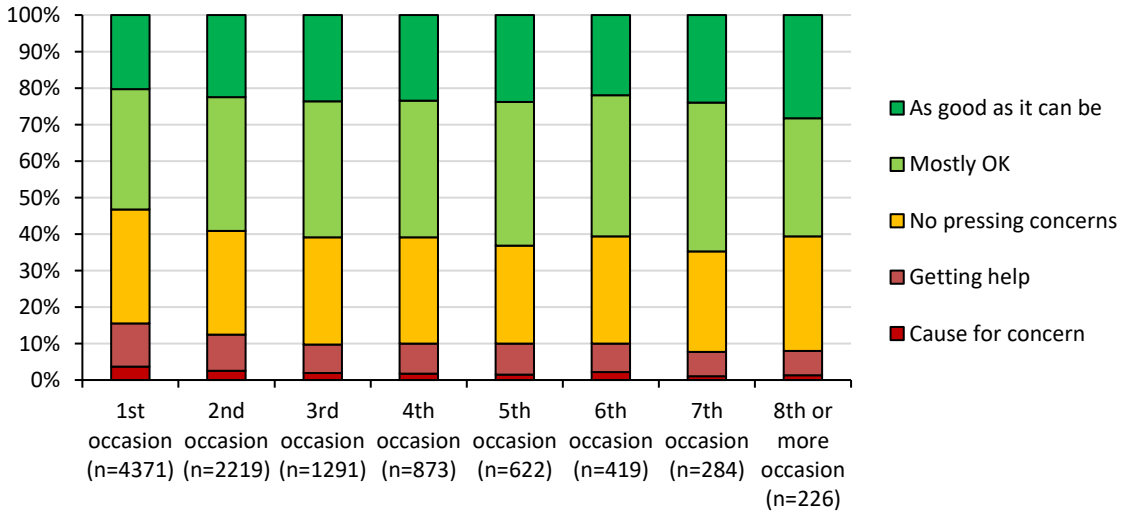
Figure 5 Changes in Carers Star 'The caring role' domain (Jul 2018 to Sep 2020)



5.5.2.3 Carers Star: 'Managing at home' domain

Figure 6 shows changes in scores for the Carers Star 'Managing at home' domain across eight (or more) time points between July 2018 and October 2020. This domain showed relatively little overall change over the period, other than a moderate increase in the proportion of carers reporting 'as good as it can be' or 'mostly OK' in the second and third time points. However, this was not surprising given that the majority of carers (52%) reported either 'as good as it can be' or 'mostly OK' at the first time point. There was a corresponding decrease in the proportion of carers reporting 'cause for concern' or 'getting help' at these time points.

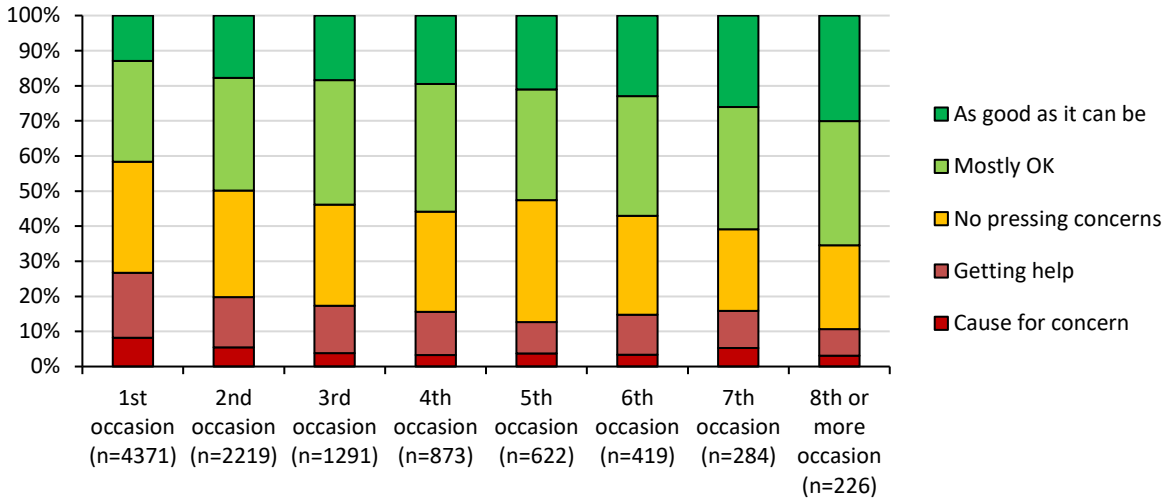
Figure 6 Changes in Carers Star 'Managing at home' domain (Jul 2018 to Sep 2020)



5.5.2.4 Carers Star: 'Time for yourself' domain

Figure 7 shows changes in scores for the Carers Star 'Time for yourself' domain across eight (or more) time points between July 2018 and October 2020. For this domain, there is a moderate increase in the proportion of carers reporting either 'as good as it can be' or 'mostly OK' over the period. At the first time point, 42% of carers reported one of these two responses. This increased to 65% by the last time point. There was a corresponding decrease in the proportion of carers reporting either 'cause for concern' or 'getting help' over this period. The proportion of carers reporting one of these two responses decreased from 28% at the first time point to about 10% by the last time point.

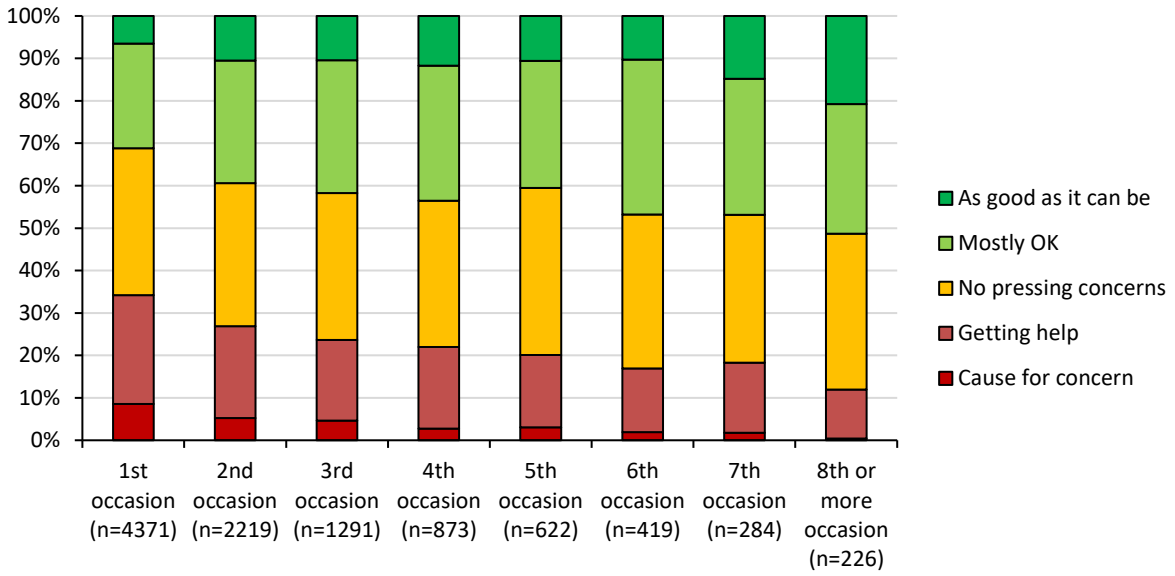
Figure 7 Changes in Carers Star 'Time for yourself' domain (Jul 2018 to Sep 2020)



5.5.2.5 Carers Star: 'How you feel' domain

Figure 8 shows changes in scores for the Carers Star 'How you feel' domain across eight (or more) time points between July 2018 and October 2020. Again, this domain showed a moderate increase in the proportion of carers reporting either 'as good as it can be' or 'mostly OK' over the period. At the first time point, 30% of carers reported one of these two responses. This increased to more than 50% by the last time point. There was a corresponding decrease in the proportion of carers reporting either 'cause for concern' or 'getting help' over this period. The proportion of carers reporting one of these two responses decreased from 34% at the first time point to about 12% by the last time point.

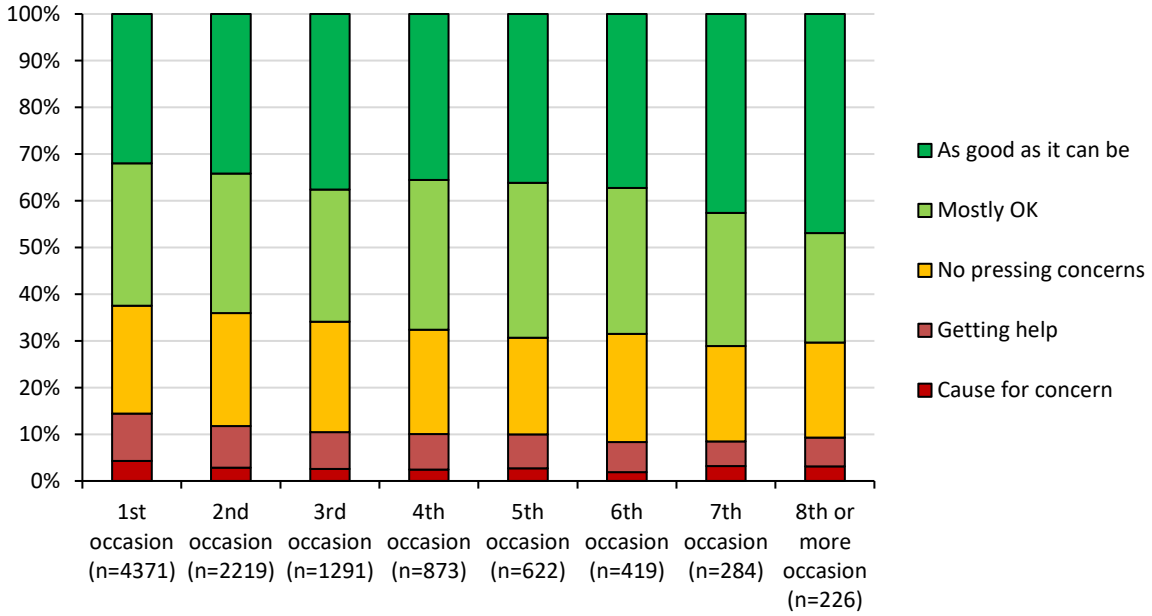
Figure 8 Changes in Carers Star 'How you feel' domain (Jul 2018 to Sep 2020)



5.5.2.6 Carers Star: 'Finance' domain

Figure 9 shows changes in scores for the Carers Star 'finance' domain across eight (or more) time points between July 2018 and October 2020. Here, the majority of carers (62%) reported either 'as good as it can be' or 'mostly OK' at the first time point. Despite this, there was a moderate increase to more than 70% of carers reporting one of these responses at the last time point. There was a correspondingly lower proportion of carers who reported either 'cause for concern' or 'getting help' (15%) at the first time point. However, this still decreased to 10% at the last time point.

Figure 9 Changes in Carers Star 'Finance' domain (Jul 2018 to Sep 2020)



5.6 Historical FCMHP data

As outlined in Section 3.1.2, prior to the introduction of the current FCMHP dataset in 2018, data were collected in a series of earlier datasets. However, the data are less complete and generally of a much lower quality than the current FCMHP MDS. The evaluation was provided with data extracted from these datasets that comprised:

- Registered clients and consumers' data;
- Contact and services;
- DASS assessments; and
- Support group, education/ training and Information sessions data.

Given the issues with the quality of these historical data, it was not possible to undertake a detailed range of analyses. However, in order to provide an historical context of the carer profile of the FCMHP, this section presents a summary of the data that was available for the evaluation.

5.6.1 Registered clients and consumers data

The demographic profile of carers who received services during this period is shown at Table 14. Over the different reporting periods between October 2008 to June 2018, a total of 16,506 clients were registered by seven CMOs comprising Aftercare (10%), ARAFMI (3%), Care Assist (51%), Carers NSW (10%), Centre Care (7%), Mission Australia (7%) and Uniting Care Mental Health (12%).

Client data were collected in the FCMHP MDS Versions 1 to 6 using the 'Family and Carers Monitoring Form 1: Registered Clients' quarterly between October 2008 to June 2018. For carers who received assistance in subsequent reporting periods, these data were not collected again but the carers were referred by their "Client ID" provided at the time of first completion. The client register data included carers' demographic characteristics, length of caring role, initial carers' needs and the number of people of caring for.

The vast majority of carers were adult aged 40 and over (81%), female (76%), spoke English language at home (91%), were not from a CALD background (78%), had been in caring role for over one year (79%), were not in labour force/unemployed or retired (57%) and were caring for one consumer (89%). In terms of initial carer needs, 74% of carers required information support, followed by emotional support (67%), education and training (41%), advocacy (21%) and referral (19%).

The consumer data consisted of 18,423 consumers who had been cared/supported by 15,990 carers. The majority of consumers were cared by parents (53%), followed by partner (19%), child (11%) and sibling (7%). Almost, two-thirds of consumers lived with their carers (65%).

Table 14 Carer demographic characteristics (Oct 2008 and Jun 2018)

Characteristics	Number of carers n=16,506	Percentage %	Characteristics	Number of carers n=16,506	Percentage %
Name of the CMO			CALD		
Aftercare	1,703	10.3	Yes	2,540	18.0
Arafmi	456	2.8	No	11,060	78.3
Carer Assist	8,442	51.2	How long in caring role		
Carers NSW	1,645	10.0	0	59	0.4
Centre Care	1,064	6.5	≤ 6 months	1,177	7.7
Mission Australia	1,144	6.9	6 months- 1 year	1,944	12.7
Uniting Care mental Health	2,052	12.4	2-5 years	4,463	29.0
Gender			6-10 years	3,050	19.8
Female	11,987	76.0	11-20 years	2,754	17.9
Male	3,722	23.6	Employment status		
Not stated	58	0.4	Full-time	3,297	21.7
Age group			Part-time	2,390	15.8
less than 20	566	4.6	Casual	904	6.0
20-29	597	4.9	Unemployed	2,910	19.2
30-39	1,303	10.7	Retired or not in labour force	5,673	37.4
40-49	2,527	20.7	Initial client needs		
50-59	3,315	27.2	Information	12,291	74.5
60-69	2,552	20.9	Emotional	11,125	67.4
70-79	1,086	8.9	Education	6,709	40.7
80 and over	241	2.0	Advocacy	3,427	20.8
Language speaking at home			Referral	3,187	19.31
English	14,007	90.9	Number of people cared for		
Non-English	1,399	9.1	1	13,439	88.5
Indigenous status			2	1,421	9.4
Indigenous	1,838	14.0	More than 2	313	2.1
Non-Indigenous	11,321	86.0			

5.6.2 Contacts and service data

A total of 330,513 records of contacts and services were observed for carers who received assistance between October 2008 and June 2018. Around 74% of contacts and services data (n=223,588) were for registered clients, and 26% (n=78,793) were for non-registered clients excluding 28,133 missing information (Table 15). However, nearly one third of contacts and services data (n=104,648) did not have any client ID and so the number of distinct carers is unknown. The contacts and service data (n=225,866) which have a carer ID were reported by

20,503 distinct carers of which 15,141 carers also included in the registered clients and consumers datasets described earlier.

In terms of action/results, around 68% of contacts and services data reported information support, emotional support (31%), advocacy support (10%) referral (4% internal referral and 5% external referrals) and other reasons (8%). The action/results were not mutually exclusive as a record of service and contact can include multiple actions/results.

Table 15 Number of contacts and services (Oct 2008 to Jun 2020)

Year	Reporting period	Number of contacts and services		Total
		Registered clients	Non registered clients	
2008	1	2,539	1,013	3,552
2009	2	3,278	1,211	4,489
	3	3,897	1,234	5,131
	4	4,629	1,617	6,246
	5	3,466	1,922	5,388
2010	6	5,007	1,776	6,783
	7	6,024	1,642	7,666
	8	3,190	1,345	4,535
	9	2,051	1,019	3,070
2011	10	4,025	2,387	6,412
	11	4,643	2,224	6,867
	12	5,299	1,301	6,600
	13	4,914	2250	7,164
2012	14	5,309	2,437	7,746
	15	5,396	1,357	6753
	16	5,314	1,634	6,948
	17	5,340	2,842	8,182
2013	18	5,622	2,063	7,685
	19	5,681	1,605	7,286
	20	6,255	2,643	8,898
	21	6,040	2,744	8,784
2014	22	7,830	1,925	9,755
	23	7,025	2,712	9,737
	24	7,547	2,359	9,906
	25	8,409	1,702	10,111
2015	26	7,968	3,050	11,018
	27	8,720	2,204	10,924
	28	7,840	2,354	10,194
	29	8,301	1,910	10,211
2016	30	6,344	2,980	9,324

Year	Reporting period	Number of contacts and services		Total
		Registered clients	Non registered clients	
	31	5,947	2,047	7,994
	32	6,550	2,350	8,900
	33	5,562	2,179	7,741
2017	34	7,062	2,159	9,221
	35	6,801	2,604	9,405
	36	6,497	1,842	8,339
	37	5,587	2,074	7,661
2018	38	6,638	1,517	8,155
	39	5,040	2,559	7,599
	Total	**223,587**	**78,793**	**302,380**

5.6.3 DASS assessment data

A total of 13,811 assessments were completed between October 2008 and June 2018, using the DASS. The majority of the assessments were completed at the initial stage (58%, n=7,937) and 42% (n=5,785) were completed at follow-up (Table 16). Data were available on 8,051 DASS assessments for distinct carers. Of these, 5,518 carers received DASS assessment only at one reporting period while 2,533 carers received the assessment from between two and 22 reporting periods. There was a significant improvement in the mean score of depression, anxiety, and stress in the follow-up time compared with the initial assessment ($p<0.001$) (Table 16). For example, moderated anxiety (mean score: 10.4) was reported at initial assessment which improved to mild anxiety (mean score: 8.9) at follow-up.

Table 16 DASS initial assessment and follow-up scores

DASS Assessment	Initial assessment (n=7,937)		Follow-up (n=5,785)	
	Mean	Standard deviation	Mean	Standard deviation
Depression	13.5	10.9	11.6	10.6
Anxiety	10.4	9.6	8.9	9.3
Stress	17.8	10.5	15.2	10.9

Note: All the differences between mean score at initial assessment and at follow-up were significant at $p<0.001$.

5.6.4 Support group, education/ training and Information session data

In total, 11,551 records of support groups, education/training and information sessions were reported between October 2008 and June 2018. Just over two-thirds of these records (41%, n=4,652) involved support groups, followed by education and training (35%, n=3,996) and information sessions (24%, n=2,720).

The number of registered carers that participated in these sessions was 7,199. However, the data also included 7,822 non-registered carers and 6,833 carers that could not be linked to

the activity data. Overall, this dataset was not considered to be of sufficient quality to conduct any further analysis regarding participants' characteristics or completed activities.

5.7 LHD FCMHP dataset

As outlined in Section 3.1.3, LHDs are required to report FCMHP data to the Ministry on a six-monthly basis. This is included as a part of the monitoring of a suite of NSW Government Mental Health Reform Initiatives. A copy of the LHD reporting template is provided at Appendix 3.

FCMHP data were provided by the Ministry for three six-month reporting periods from July 2019 to December 2020. Data for the most recent period of January to June 2021 were not readily available as a result of an easing of reporting requirements due to COVID-19 pandemic-related pressures on resources.
In interviews and discussions over the course of the evaluation, some LHDs indicated that the mandatory data are able to be extracted from the electronic medical record (eMR) system. However, other LHDs noted anomalies in the eMR data, potentially arising from inconsistent data entry practices. Detailed information about staffing and program activity is also recorded manually by many LHDs, which is used either to source all the data (where the eMR system does not support the extraction), or as a supplementary data source.

Examples of additional program information that was reported includes; further breakdown of activity hours, details of combined program activities, travel time, conferences and meetings, leave periods, positions vacant and recruitment activities.

Prior to the implementation of the current reporting template in July 2019, a qualitative approach was used for reporting which involved LHDs providing a written summary of program activities. These reports were not in a standard format and were not used in the evaluation.

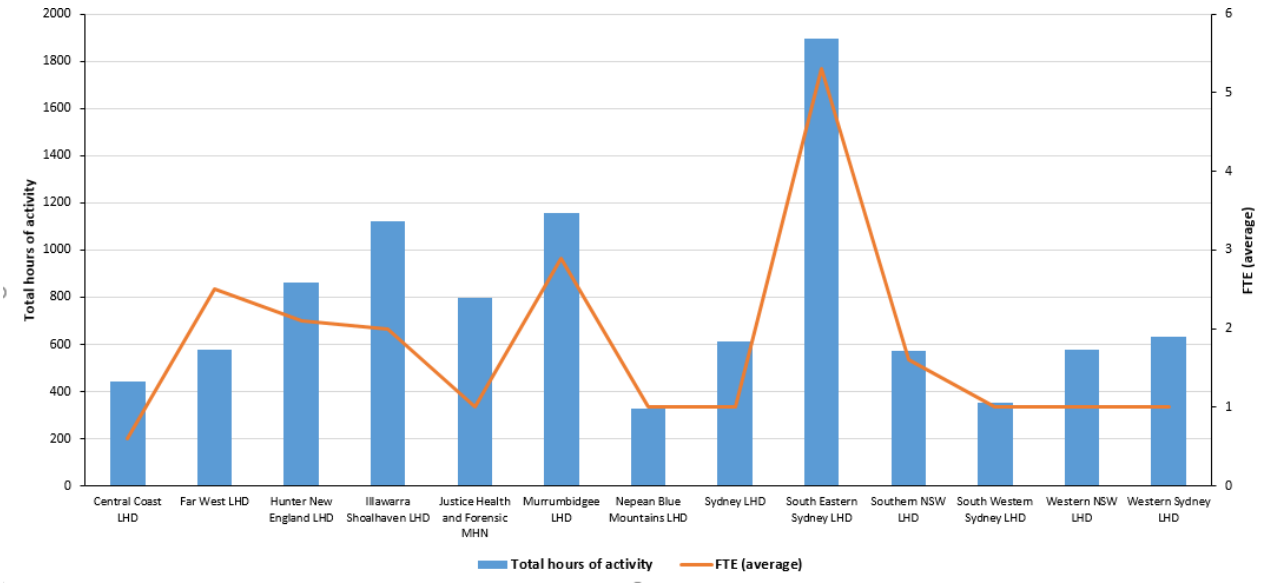
5.7.1 Summary of LHD data

There were deficiencies observed in the reporting which need to be considered in analysis and interpretation of the data. From an expected total of 48 reports, there were 42 reports provided (14 for Jul-Dec 2019, 15 for Jan-Jun 2020, 13 for Jul-Dec 2020). Data quality issues were observed including:

- FTE and activity hours can include a combination of FCMHP and other program data in some reporting (the reporting instructions request that where possible, staff positions or activity that has been supplemented by other funding is not combined into the data reported for the program);
- FTE for vacant positions and leave period are included in the total FTE in a number of reports;
- FTE data were reported without any activity hours in one report;
- Data that is reported in the 'additional comments' text box are not consistently also included in the totals.

Figure 10 shows the total number of hours of activity by the average FTE reported by each LHD between July 2019 and December 2020.

Figure 10 Total hours of activity by FTE (Jul 2019 to Dec 2020)

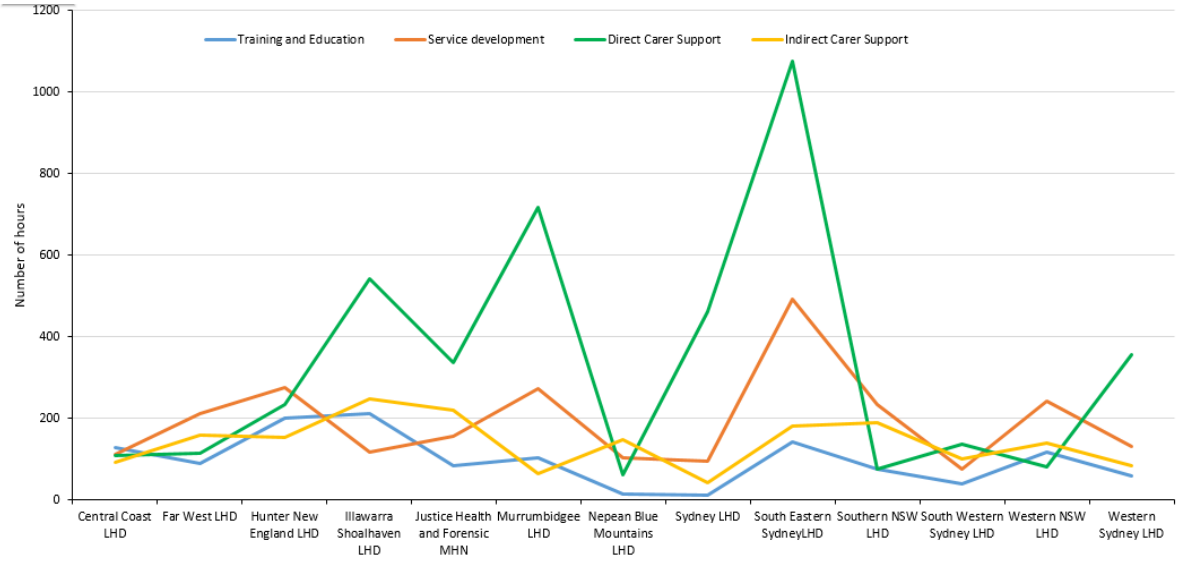


Note: Three LHDs (MNCLHD, NNSWLHD, NSLHD) are not included due to the low number of hours of activity reported

While it can be seen that there is variation in the number of activity hours compared to the FTE, any assessment about output or comparisons between LHDs based on this analysis should be treated with caution given the data inconsistencies.

Figure 11 shows the total number of hours by each activity by LHD. Of note in this chart is the prominence of direct carer support, being the activity with the highest number of hours in more than half the LHDs. This is followed by service development, then indirect carer support. Training and education has the least number of hours in more than half the LHDs and the lowest total overall.

Figure 11 Activity hours by type (Jul 2019 to Dec 2020)



Note: Three LHDs (MNCLHD, NNSWLHD, NSLHD) are not included due to the low number of hours of activity reported

While the analysis that was undertaken of the LHD data is high-level, it indicates that it has potential utility in the review and management of the FCMHP. Improving the robustness of the data collection would enhance the scope to which it could be applied.

5.8 FCMHP Carer Experience Survey

This Section presents the results of the FCMHP Carer Experience Survey. This survey was completed during August 2021 and September 2021 by 203 clients of FCMHP CMOs. It provided an important opportunity to directly explore carers' experiences of the program. The process of administering the Carer Experience Survey was outlined in the Section 3.1.4. The survey instrument is provided at Appendix 4.

5.8.1 Carer Experience Survey – Participant characteristics

Table 17 compares the profile of survey participants with the 6,201 clients in the on which FCMHP MDS data were available. The age profile of survey participants was noticeably older compared with the profile across the program (>80% of survey participants aged over 50 compared 68% across the program). Male carers were also under represented in the survey participants (11% vs 21%). The vast majority of survey participants (81%) were born in Australia which is consistent with the FCMHP profile, whereas most survey participants (95%) reported 'English' as the primary language spoken at home, which was higher than the overall FCMHP profile (84%).

Almost two-thirds (n=132, 65%) of survey participants lived with the person they support. Many of those who were not living with the person they support, live independently (n=41, 20%), with other family member or in supported accommodation (n=12, 6%), and other (n=13, 6%). Nearly half of the carers (n=99, 49%) supported their son or daughter, followed by parents (n=54, 26%), and partner/spouse (n=31, 15%). Interestingly, more than half of the survey participants (n=114, 57%) had been in a supporting role for 10 or more years. Only a

small proportion (n=4, 2%) had been in a supporting role for less than one year, and none for less than six months.

Table 17 Carer Experience Survey - Person-based characteristics

Person-based Characteristics	Carer Survey (n=203) Jul-Aug 2021		% in the FCMHP-Jul 2018-Sep 2020 (N=6201)
	n	%	
Age group			
<30	3	1.5	5.3
30-39	12	5.9	8.5
40-49	23	11.3	18.5
50-59	59	28.9	28.9
60-69	60	29.4	22.8
70+	47	23.0	16.0
Sex			
Female	179	87.8	78.8
Male	23	11.3	21.2
Non-binary/prefer not to say	2	0.9	-
Country of birth			
Australia	161	81.3	78.3
Overseas	37	18.7	21.7
Language			
English	179	94.7	84.1
Other than English	10	5.3	15.9
Live with the person you support			
Yes	132	64.7	-
No*	72	35.3	-
Relationship			
Spouse/partner	31	15.3	-
Son or daughter	99	48.8	-
Parent	55	26.6	-
Brother or sister	4	2.0	-
Friend	9	4.4	-
Other	6	3.0	-
Time in supporting role			
Less than 6 months	-	-	-
6 months to less than 1 year	4	2.0	-
1 year to less than 2 years	18	9.0	-
2 years to less than 5 years	32	15.9	-
5 years to less than 10 years	34	16.4	-

10 years or more	114	56.7	-

* live independently: 41 (20%) and other, including supported accommodation or other family member (25, 12%)

5.8.2 Carer Experience Survey - Service-related characteristics

Table 18 shows the characteristics of survey participants. The distribution across CMOs was almost proportional to the number of carers across CMOs except for a noticeable over representation from Mission Australia (18% vs 8%) and under-representation from One Door Mental Health (32% vs 50%). In addition, a small proportion of carers (n=14, 7%) participated from the JH&FMHN.

A substantial proportion of survey participants (n=79, 39%) had been involved in the FCMHP for three or more years with only a small proportion (n=24, 12%) for less than six months. Over half the survey participants (n=101, 51%) were involved in any of the services and activities provided by the FCMHP on a monthly basis, with nearly one-fifth (n=38, 19%) involved once every three months. While a noticeable proportion survey participants (n=38, 19%) had been involved more frequently (once in every one or two weeks), a significant proportion (n=21, 11%) had less frequent involvement in the FCMHP program activities.

Four out of every five carers reported that they are satisfied with the frequency of their involvement in the FCMHP. The reasons offered by those who were not satisfied included that they had paid employment commitments, services offered were not always useful or relevant, service hours were not suitable, and travel required to get to service location. The vast majority of survey participants (n=168, 82%) were planning to continue to be involved with FCMHP with around 16% (n=33) not sure about their ongoing involvement. Most of the survey participants (n=197, 97%) completed the survey by themselves.

Table 18 Carer Experience Survey - Service-related characteristics

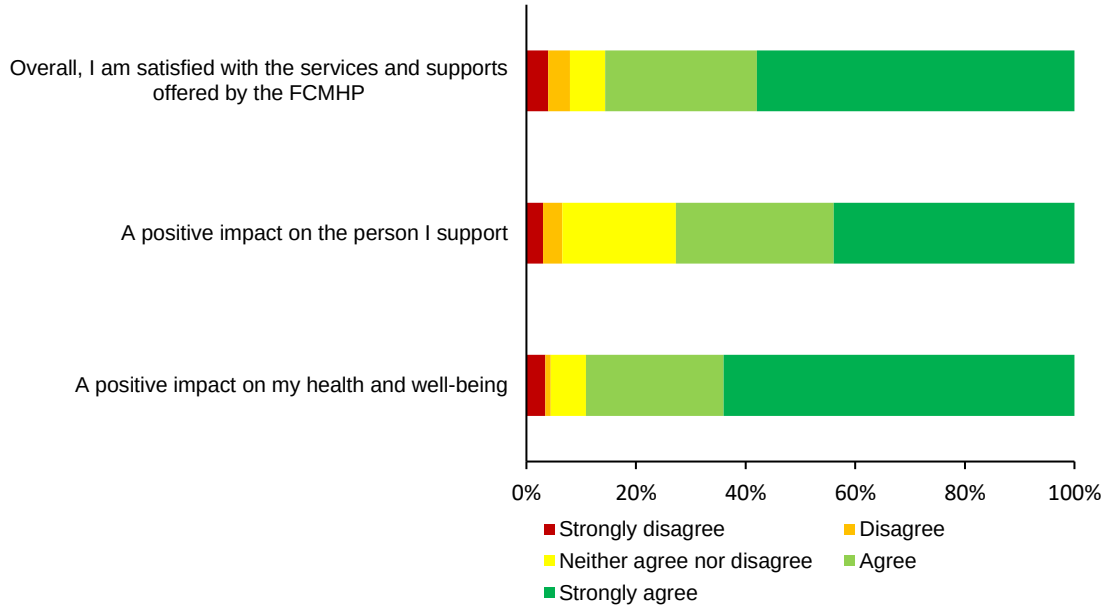
Service-based Characteristics	Carer Survey (n=204) Jul-Aug 2021		% in the FCMHP-Jul 2018-Sep 2020 (N=6,201)
	n	%	
Community Managed Organisation (CMO)			
Catholic Care Wilcannia-Forbes	17	8.3%	7.7%
Mission Australia	37	18.1%	7.7%
One Door Mental Health	65	31.9%	50.4%
Uniting	38	18.8%	18.3%
Stride	33	16.2%	16.0%
Justice Health and Forensic Mental Health Network	14	6.9%	-
Time in FCMHP			
Less than 6 months	24	11.8%	-
6 months to < 1 year	27	13.2%	-
1 year to < 2 years	47	23.0%	-
2 years to < 3 years	27	13.2%	-

Service-based Characteristics	Carer Survey (n=204) Jul-Aug 2021		% in the FCMHP-Jul 2018-Sep 2020 (N=6,201)
	n	%	
3 years or more	79	38.7	-
How often involved in FCMHP			
Every 1 to 2 weeks	38	19.2	-
Once a month	101	51.0	-
Once every 3 months	38	19.2	-
Once every 6 months	12	6.1	-
Once a year	9	4.6	-
Are you satisfied with how often you are involved in FCMHP?			
Yes	163	79.9	-
No	41	20.1	-
Are you planning to continue to be involved with the FCMPH?			
Yes	168	82.4	-
No	3	1.5	-
Not sure	33	16.2	-
Did someone help you complete the survey?			
No	197	96.6	-
Yes (FCMHP staff, family member or other)	7	3.4	-

5.8.3 Impact of the services and support offered by the FCMHP

Figure 12 presents carers' levels of agreement regarding the impact of and overall satisfaction with the services and support offered by the FCMHP. The vast majority of carers reported they 'strongly agree' or 'agree' that the services and support offered by the FCMHP have a positive impact on their health and well-being (86%) and on the person they support (73%). However, around 21% of carers reported 'neither agree nor disagree' about the impact of the services and support on the person they support. Overall, nearly nine out ten carers reported 'strongly agree' or 'agree' regarding their satisfaction with the services and supports offered by the FCMHP.

Figure 12 Levels of agreement between impact and satisfaction with FCMHP (n=203)



5.8.4 Carer Experience Survey - Carers' involvement in the FCMHP

One out of every two survey participants reported that they received 'One-to-one information and support (including referrals)', with 32% also participating in one of more other activities (Table 19). Only 15% of the survey participants reported their involvement with 'One-to-one education and training' with most of them also using other services.

Nearly half of the survey participants (n=98, 48%) reported that they were involved in 'Group information and support', and many of them (n=60, 30%) also reported being involved with other activities offered by the FCMHP. Just less than one-third of survey participants (n=65, 32%) participated in 'Group education and training'. Only 16% received 'Advocacy services' and 14% 'Respite services', the majority of which were in combination of other services.

Those who reported being involved in activities in the 'Other' category (n=23, 11%) were involved with a unique range of activities which were not included in Carer Survey questionnaire.

Overall, there are noticeable differences between the proportion of carers involved in different activities reported in the Carer Survey and in the whole FCMHP program, which might partly be explained due to variation in the list of activities included in the survey.

Table 19 Carer Experience Survey - Involvement in the FCMHP activities

Activity	Carer Survey (Jul-Aug 2021)						% in the FCMHP-Jul 18-Sep 20 dataset (n=6,201)
	Single activity (n=204)		Combination with other one or more activities (n=204)		Overall (n=204)		
	n	%	n	%	n	%	
One-to-one information and support (including referrals)	37	18.2%	64	31.5%	101	49.8%	85*%
One-to-one education and training	4	2.0%	27	13.3%	31	15.3%	20%
Group information and support	38	18.7%	60	29.6%	98	48.3%	15%
Group education and training	19	9.4%	46	22.7%	65	32.0%	28%
Advocacy services	8	3.9%	24	11.8%	32	15.8%	24%
Respite services	7	3.4%	21	10.3%	28	13.8%	-
Other	23	11.3%	-	-	23	11.3%	-

*Not included referrals (25%).

Table 20 presents the length of time survey participants were involved in the FCMPH relative to the length of time in a supporting role. While the majority of survey participants had been in a caring role for more than 10 years, the corresponding time of involvement in the FCMHP is relatively low for many carers. For example, almost 40% of carers who have been in a support role for more than 10 years had been involved in the FCMHP for less than two years. The corresponding figures were 42% for carers who have been in caring role between 5-10 years and 52% for 2-5 years in caring role.

Table 20 Carer Experience Survey - Length of time in the FCMHP by time as a carer

Time in FCMHP	Time in the supporting role									
	Less than 1 year		1 - 2 years		2 - 5 years		5 to 10 years		≥10 years	
	n=4	%	n=18	%	n=32	%	n=34	%	n=114	%
Less than 6 months	2	50.0	4	22.2	3	9.7	4	12.1	10	8.9
6 months- 1 year	1	25.0	4	22.2	6	19.4	3	9.1	13	11.5
1-2 years	0	0.0	10	55.6	7	22.6	7	21.2	22	19.5
2-3 years	0	0.0	0	0	10	32.3	5	15.2	12	10.6
3 or more years	1	25.0	0	0	5	16.1	14	42.4	56	49.6

6 Results: Qualitative data

Qualitative data were a crucial source of information for the evaluation. These data supplemented the quantitative data reported in the previous chapter, and facilitated a more robust understanding of the issues that emerged as being important for the program.

The data collection was undertaken by the evaluation team at different stages as outlined in Section 3.2. Data were collected during semi-structured interviews with carers, LHDs, CMOs, specialist networks and peak bodies. In addition, the Carer Experience Survey included several open-ended questions that provided carers with an opportunity to provide feedback regarding their experience with the program.

The qualitative data were analysed using an approach known as the Framework Method.[38] This is a well-established thematic analysis process that is particularly applicable when using data from semi-structured interviews. It enables raw data to be summarised and sorted for analysis according to the different themes that emerge both within and across interviews.

This section presents the results of a thematic analyses of all qualitative data collected during the evaluation. Results included in the interim report are re-presented to provide a consolidated set of evaluation findings. Importantly, these results have been significantly expanded to reflect the additional data collected since the completion of the interim report. This includes additional key stakeholder interviews, as well as carer interviews and the open-ended questions in the Carer Experience Survey.

Section 6.1 summarises the qualitative data sources included in the analysis. Sections 6.2 to 6.4 present the results of the analyses structured around three broad subject areas:

- Program structure, funding and governance arrangements;
- Service effectiveness and meeting needs;
- The impact of the COVID-19 pandemic.

6.1 Overview of qualitative data sources

6.1.1 Key stakeholder interviews

A total of 30 key stakeholder interviews were conducted during the evaluation, with participants representing 26 organisations/groups, including all LHDs and JH&FMHN, the contracted CMOs, a range of peak bodies, a carer representative, and the Ministry. The breakdown of interviews across the two phases of the evaluation is shown in Table 21. Interviewees from the LHDs comprised staff employed in the FCMHP, or with the FCMHP included in their portfolio, and Directors of Mental Health from four LHDs.

[38] Gale N K, Heath G, Cameron E, Rashid S & Redwood S (2013) Using the framework method for the analysis of qualitative data in multi-disciplinary health research, *BMC Medical Research Methodology*, 13 (117).

Table 21 FCMHP Evaluation stakeholder interviews

Organisation/group		Number
Phase 1 (n = 15)	**Phase 2 (n = 16)**	
Local Health Districts (LHDs)		**19**
Far West	Central Coast	
Hunter New England	Mid North Coast	
Illawarra Shoalhaven*	Murrumbidgee	
Murrumbidgee	Nepean Blue Mountains	
Nepean Blue Mountains	Northern Sydney	
Northern NSW	South Eastern Sydney	
Western Sydney	South Western Sydney	
	Southern NSW	
	Sydney	
	Western NSW x 2	
	Western Sydney	
Specialist Networks		**1**
Justice Health and Forensic Mental Health (JH&FMHN)		
Community Managed Organisations (CMOs)		**6**
CatholicCare Wilcannia Forbes	Stride	
Mission Australia	One Door Mental Health x 2	
Uniting		
Peak bodies/other stakeholders		**5**
Carer Representative	Ministry of Health	
Mental Health Carers NSW		
Mental Health Commission NSW*		
Specialist CALD representative		
Total		**30***

*Represented both Illawarra Shoalhaven LHD and the NSW Mental Health Commission

6.1.2 Carer interviews

Carers who completed the Carer Experience Survey were invited to express interest in participating in an interview to discuss their experiences with the FCMHP in more detail. Fifteen individuals were selected comprising a sample of carers from LHDs, CMOs and from different age groups and gender. The fifteen interviews were held between July 2021 and September 2021. The breakdown of carers interviewed is shown in Table 22.

Table 22 Carer interviews: participant profile

Organisation/group	Number	Organisation/group	Number
Local Health Districts (LHDs) and number of interviews (n=14)			
Central Coast	1	Northern	1
Far Western	1	South East Sydney	2
Illawarra Shoalhaven	1	Southern	1
Murrumbidgee	2	Western NSW	2
Specialist Network - Number of interviews (n=1)			
Justice Health and Forensic Mental Health (JH&FMHN)	1		
Community Managed Organisations (CMOs) - Number of interviews (n=15)			
Catholic Care Wilcannia-Forbes	3	One Door Mental Health	3
Mission Australia	1	Uniting	4
Stride	3	No CMO	1
Age group - Number of interviews (n=15)			
Under 30	0	50-59	3
30-39	1	60-69	5
40-49	0	70+	6
Gender - Number of interviews (n=15)			
Female	12	Other or unspecified	0
Male	3		

6.1.3 The FCMHP Carer Experience Survey (open-ended question responses).

The Carer Experience Survey (refer Appendix 4) included four open-ended questions that invited respondents to provide additional comments as part of their response:

Are you planning to continue to be involved with the Family and Carer Mental Health Program? Please comment on your response.

(How) has the COVID-19 pandemic changed how you interact with or view the Program?

What do you like most about the Family and Carer Mental Health Program?

What could be improved about the Family and Carer Mental Health Program?

The vast majority of the 203 survey responses included a response to at least one of these four questions.

6.2 Results: Program structure, staffing and resources

6.2.1 Structure and governance

The overarching FCMHP structural arrangements, where funding and performance agreements are managed centrally by the Ministry, were widely supported by program stakeholders. Participants felt that this arrangement provides a valuable level of consistency across the program.

Within this structure, CMOs and LHDs negotiate SLAs to ensure an understanding of, and agreement to, respective roles and responsibilities. The SLAs cover issues such as referrals, exchange of information, sharing resources, dispute resolution and risk management. Again, this arrangement was supported by both CMO and LHD providers.

The role of the FCMHP statewide steering committee was also supported by participants. This group also provides the opportunity to identify strategic opportunities and needs, such as resource development, significant contributions to policy, planning and documentation as well as provide support to local LHD and CMO activities and other groups to support carers. Most participants feel that this aspect of the Program is working well but that there could be greater emphasis on strategic aspects.

CMO structures

The structure of CMO services within the FCMHP is broadly consistent across the program. However, services are tailored to address local population needs and constraints. Differences in organisational structures also influences the approach to providing services across CMOs. This issue is discussed in more detail in the context of its implications on FCMHP staffing structures in Section 6.2.2 below.

From a structural perspective, some common elements were identified as being crucial to the success of the CMO model. One was the availability of a suitable contact person to advocate for carers. This was described by one participant:

> *A person that a carer can reach out to, that's trusted, that's local, knows the services, has contacts with the services, is able to build a service delivery plan with the families and carers. (CMO)*

The importance of CMO structures promoting strong partnerships with LHDs was also identified by both CMO and LHD participants. The importance of the CMO Program Coordinator role in particular was identified in this context.

LHD structures

LHDs are largely autonomous in determining their approach to delivering FCMHP services. This is reflected in the different approaches in practice across NSW. Some program coordinators spend considerable time delivering services directly to carers. In other LHDs, this role does not work directly with carers at all, but focuses on organising other staff to assist carers, and coordinating training for mental health, clinical and other health care staff.

This de-centralised approach provides flexibility and the capacity for LHDs to deliver services tailored to local circumstances. Some participants felt that a more structured and coordinated approach may reach more carers, particularly in rural and remote areas. It was suggested that ideally LHDs could employ a clinical lead that has direct access to a larger workforce. The fundamental importance of executive level support for the program was also identified in this context.

Some participants felt that more definition in the way the program is delivered within LHDs may allow for a more strategic and coordinated approach to providing carer services across all of NSW. This includes identifying where clinical services are needed as well as services for groups such as CALD and Aboriginal and Torres Strait Islander people.

Increased communication between LHDs was identified as an important opportunity for the program. For example, learning from non-metropolitan areas that often work remotely and operate in different ways. One LHD participant spoke about the value of co-location of services to enhance service delivery to carers.

> *Because I know that when that person was up there in (location), the interaction between (the person) and the staff was brilliant, (the person) was able to attend handover meetings and allocation meetings. The referral was really straightforward. They trusted (the person), because they saw (them) a lot. (The person) understood the challenges and limitations of what they could do. I think it worked really, really well and that hasn't been possible, because everywhere in our LHD we are bursting at the seams but I think that that would be a structural change that I would make. (LHD)*

KPIs and data collection

Participants were broadly happy with the current CMO KPIs. The targets are realistic, which allows the program to offer more than "just a bit of handholding". The opportunity to provide feedback in the development of the KPIs was considered to be a positive opportunity for CMOs. It was suggested that a greater focus on a case management approach rather than just specific tasks or occasions of service would improve the utility of the KPIs.

Participants expressed mixed views in relation to data collection. Some felt that data collection focussed too much on hard data rather than carer experiences:

> *I think there should be a bit more emphasis in collecting the good news stories, because they tell the story of what the person's achieved and what the program's done to assist in that process. (CMO)*

Participants spoke about having their own data collection as well as the FCMHP MDS. LHDs often collected different stats, both from CMOs and from other LHDs. Some participants expressed the view that that the differences made comparisons more difficult as well as the ability to track funding and how it was being spent. Some CMOs discussed having their own data system as well as the MDS to inform their practice.

6.2.2 Staffing

There is considerable variation in staffing structures across the FCMHP that is particularly evident across LHDs.

Funding provided from the Ministry determines the level of staffing that the CMOs are able to employ in the program, and largely dictates how the programs are staffed in the LHDs.

Participants generally reported the program was not adequately staffed to meet the current level of need.

> *If you were going to give me my wish list it would be to increase our team, because obviously we can only do so much when we cover a big area. I would like to see not only an increase to the LHD program structure, but also to CMOs. (LHD)*

> *…we've had a pretty stagnant funding since day dot… And even though they've given CPI increases, it hasn't actually increased the funding of people on the ground as time has gone on. (CMO)*

In addition to funding constraints, workforce availability can also determine the services able to be provided by the FCMHP. Participants noted that there can be difficulties in recruiting staff to the program, particularly in regional areas, and positions could remain vacant for extended periods. Some also commented that employment conditions were not always conducive to attracting and retaining staff. While acknowledging that this is a broader issue across the sector, it was reported that high staff turnover can present challenges in maintaining relationships and providing consistent services. Conversely, there were those whose experience was of a fairly stable workforce.

> *What I've found, if anything, is that they're very committed, and I know we could say that about a lot of people that work in mental health, but, genuinely, passionately committed and that's their focus. I've never heard them talk about their pay or conditions. (CMO)*

Staffing profile

The staffing profile was found to be similar across the CMOs. Generally, this comprised a program co-ordinator/manager role, who might either work solely on FCMHP or across other programs as well, along with a team of support workers. Caseloads for the number of program staff were reported as being manageable by some CMO providers, but challenging for others.

> *We don't want to get to a point where we put ourselves in a really dangerous predicament and we've got unsafe caseloads. It is hard. … Ideally if we had more staff, that's what would make things more accommodating for us. (CMO)*

To the extent that they are able, the CMOs generally structure their teams according to the demographics of the community they are servicing, as well as for the specific needs of their partner LHDs.

There are staffing related risks to the delivery of the program in some LHDs, particularly where there is no designated FCMHP role, rather it is 'tacked on' to a staff member's portfolio. Issues were also highlighted regarding the risk associated with having only one person in the FCMHP role. In addition to the inability to provide adequate services, these included there being no program coverage when the incumbent is on leave or the role

becomes vacant, and the need to 'start from scratch' when a new occupant comes into the program.

> *… but when I go, I'm not sure what will happen. (LHD)*

> *In the smaller LHDs the economies of scale mean that when you're in the district office there isn't as much funding to go around for people to hold specialty positions. (LHD)*

> *I think that if you've just got one FTE, it's going to be impossible for that one FTE to meet everybody's needs… (LHD)*

Some LHDs split the available FTE across two or more part time positions, with staff often having to work across multiple programs. This was considered to be of benefit as it creates an 'FCMHP team'. Some participants experience was of a crossover where programs 'dovetail in very nicely', and another describing it as enabling them to 'interweave families and carers into everything that I do' (LHD).

> *If you want to make something a really key important part of any service, you need to embed it, you need to move it beyond one staff member or two or three. It needs to become, I guess, almost a little bit of a workforce in itself. (LHD)*

The importance of having program staff physically present on site was emphasized. This maximises the profile of the program and ensures it is embedded into the service, as well as enabling supports and other services to be provided directly to families and carers - where this is the model of program delivery.

> *And we also see success. We can see cultural shifts locally. Like if you've got someone in the building and in the lunchroom, hanging around in meetings all day, everyday people just start to get it. It just happens. (LHD)*

This is a challenge both for staff in regional areas, to provide coverage across large geographical areas, as well as LHDs that have large populations and multiple inpatient and community mental health services. Inadequate staffing is reported to have resulted in inequitable program delivery.

> *…how you could ensure it's not the luck of, if you live in [location], you might get the access of that worker, versus if you live in [other location], no, you don't. (LHD)*

> *You need to resource things properly in order for them to work. And you can't split one position across [multiple] physical sites. It just doesn't work. (LHD)*

One LHD participant reported that they '…beg, borrow, and steal bits of FTE' from other funding sources to employ additional FCMHP staff. Some LHDs are able to utilise staff that are not directly employed in the FCMHP and others rely on the CMO partner organisation to supplement the program on site. There was consensus from participants that a more adequate level of staffing was needed in the LHDs.

Skill mix

Staff in the CMOs are generally required to have a tertiary qualification, or be currently undertaking study, or in some cases relevant industry experience is acceptable. In addition to program manager and team leader roles, the scope of the majority of the roles is confined to support work. One CMO has an education and training co-ordinator position as a part of the program. Participants from the LHDs reported a broad range of skill-mix, from non-clinical staff, including non-graduate roles and qualified staff, through to clinical roles, such as positions that are multi-disciplinary and psychiatrists.

Many participants identified a 'gap' in service provision for families and carers who would benefit from counselling and/or family therapy. While there is a small minority of LHDs that offer this level of clinical support as part of the program, it is generally not provided or it has limited availability.

> *…it's [family therapy] a very helpful intervention that could help a lot of people a little bit, and some people are great deal. And it would be really terrific if it was more generally available, but it really is hard to get in a lot of areas (Statewide Stakeholder)*

> *I think what might be missing is more of a clinical or counselling, formal counselling aspect of the program, which I think would add value… (CMO)*

Being unable to offer counselling to families and carers creates challenges for support staff, with participants noting that it 'places a lot of pressure on a workforce that that's not their role' and that it was important that there was a system where support workers could 'hand [a] carer on when it's beyond their role'(CMO).

> *It's that hard line when someone's in distress and they're telling you, and you've got to find that line between not being a counsellor or therapist and sticking in your lane, which is a tightrope. (CMO)*

There were differing opinions around whether this function should be incorporated into the services provided by the CMOs or the LHDs. One participant noted this highlighted the importance of the LHDs and CMOs working in partnership 'where we've got our clinical work, and then they're there for the extra support' (LHD).

> *The support work is brilliant, but I think you need that extra element in the team. I think it needs to evolve a little bit. (CMO)*

> *So some extra funding injected into the CMOs to actually have a bit more of a layered workforce rather than just expecting carer peer workers/ support workers to be the answer to all carer support. (LHD)*

Carer peer workers

While the commencement of the FCMHP predates the widespread recognition of the value of peer support workers, this workforce is now highly regarded within the program, by both

CMO and LHD providers. Participants reported many benefits from the inclusion of a carer peer workforce, for families and carers as well as mental health services.

> *The change I would make is to... within health, to advocate for carer peer worker in all of the LHDs. (LHD)*

> *It's also been very important about trying to get that lived experience to be a strong part of it. And I think we've seen a real uptake of the importance of lived experience in the workforce and so I think for me, that's invaluable. (CMO)*

> *I would say that there is need for carer peer worker in this space, within health. Because health is so big. Health is complex. (LHD)*

> *Oh gosh, give me carer peer workers. That would be amazing. That to me is the black hole, where I think that's a responsibility to navigate people around our service. (LHD)*

Within the FCMHP there are some identified carer peer positions, while other providers have recruited carers with lived experience into the support worker roles. Some LHDs are able to utilise peer workers working in their service to complement the delivery of the program, but participants generally called for carer peer supports to be an integral part of the program.

> *…there are a lot of carers who are employed by the program, and that does add extra credibility and assist the engagement of our cohort a great deal. (State Stakeholder)*

> *I think perhaps in delivering the program as well, making sure that it's built into the CMO's context somehow that they endeavour to have people with lived experience working on them on their teams would be really helpful, I think. (LHD)*

> *…we need kind of more support, kind of carer advocate within health... especially for our in-patient units, because it's been identified that period is a very stressful period for all carers, whether they've been caring for a long time, or they're new carers. So we need more. There is more demand for it. (LHD)*

Diversity of staff

While participants recognised the benefit of having diversity among the staff to more effectively engage and meet the needs of marginalised and/or minority groups, there are few identified positions, and the broad approach is to consider diversity in general recruitment. One participant advised they had an identified Aboriginal and Torres Strait Islander support worker position, and others reported they had recruited Aboriginal and Torres Strait Islander people into support worker roles. While there are successes in staffing the program to engage and support under-represented groups, it presents as an ongoing challenge.

> *We need Aboriginal carers. We need refugee carer reps. We need all those sort of things to be able to hear that voice, I think. (CMO)*

There was a suggestion for strategies to compensate for the deficit in representation of marginalised and/or minority groups in the staff profile, including engaging with specialist community groups and programs, as well as providing training to staff.

> *…even though we might not have the resourcing to have specialist staff to cover the broader range of people that exist in community, to help us learn, to understand... it would be really great to have training in those areas. I know the team, it has a real interest in that area, because we're not engaging those parts of the community that we want to. … We need that learning. (LHD)*

Staff training

FCMHP staff have varying opportunities for training. For support workers this may be the completion of generic courses such as community support training, through to undertaking a training pathway tailored for the program. The Certificate IV in Mental Health Peer Work (Carer Work) was highlighted by some participants as a useful training opportunity. There was a suggestion that this should be mandatory for peer workers in the FCMHP, potentially as part of a traineeship model.

Providers are able to balance time for training with managing workload, but some participants reported that there were limited training options available, and some organisations have limited resources available to develop and/or fund training.

> *We do as much development work as we can. Interesting, though, I don't see a lot of professional development, I guess, around that carer support space. (LHD)*

> *If they've (CMOs) got lots of programs under their umbrella, some of them are a lot more resourced. And then you've got others that aren't as resourced. (LHD)*

LHDs provide training opportunities for their CMO partners, with invitations to staff in-services and FCMHP events. This also promotes relationship building and the understanding of the mental health service environment.

> *Whenever I'm doing an in-service for the staff, I always invite them in. They come in and participate, and talk about the service. (LHD)*

> *Because we find that with many of our [CMO] services that they don't have that level of understanding, and why should they? That it is up to our role to be able to provide them with that. (LHD)*

One standard resource available for the FCMHP is the 'Staying Connected When Emotions Run High' training that is provided by the Illawarra Shoalhaven LHD. All CMOs complete this training, which is paid from their FCMHP funds. Some LHDs are utilising courses with external providers, such as The Bouverie Centre in Victoria, which offers a range of workforce development courses in mental health and support services, including family therapy.

Implementing training across the program with the delivery of mandated standardised courses was proposed to address the current inconsistencies. These could either be delivered within the Ministry or possibly outsourced to an external provider, with funding made available within the FCMHP.

6.2.3 Resources

The availability of program resources emerged as a key issue. While there is support for the flexibility that providers have in how the FCMHP is delivered, there is a strong call for some standard resources to be available for the program. Over the years that the FCMHP has been operating there have been attempts to develop some statewide resources, including a recent business case presented by LHDs for the development of suite of standard resources. To date these have not come to fruition due to a lack of funding and the availability of staff to undertake what is a substantial piece of work. One LHD participant noted:

> *Currently; 'the only thing is the webpage on the Ministry website' (LHD).*
>
> *A program that has been funded for more than 10 years, we need to do better. (LHD)*
>
> *We don't have a lot of Ministry-led resources or Ministry-led stuff about who it is and what we do, because it's been around for a long time, this program, and I'm not sure why... (LHD)*
>
> *It'd be nice to have an actual working document like we've got for other programs to have that there, something to work to and as a reference. (LHD)*

Resources that are developed locally are often shared for use between different providers, and there are updates and discussions about the development and sharing of program resources at the Statewide Network Meetings, hosted by the Ministry.

> *So from the point of view of each LHD sharing with each other, we do a lot of that. Just updates and who's doing what, and who's developed a brochure that they share. There's a lot of that happening and a really good support network between the LHDs and the people in my role. That's fantastic. But from the perspective of having resources that work across the state that we all could use and just generic brochures or a generic training package or something that just is pre-developed, that we don't have to keep reinventing the wheel, and that everyone can put their own logo on it and just roll it out, we've got nothing like that. (LHD).*

The evaluation was provided with many samples of the resources that have been developed and are in use locally, and it is evident there are a range of materials in use. Samples include training and education material, pamphlets and booklets, and information packs. Concerns raised around the lack of availability of standard resources include: the inequity in funding means that not all providers are able to put together resources locally, there is a waste of resources with individual providers each developing program resources, families and carers are not receiving the same information, and the material in use could become outdated

and/or it is not appropriate for its purpose. This presents a significant risk in regards to the provision of legal information.

> *So there's a lot of money being spent in individual LHDs according to who's got the resources or the time or the money to do it. Whereas if we had some better access and some more consistent stuff from the Ministry, that would be better (LHD)*

The NSW Family Focused Recovery Framework 2020-2025 (replacing the NSW Children of Parents with a Mental Illness (COPMI) Framework for Mental Health Services 2010-2015) is a program that aligns with FCMHP, and was cited as a good example of a program that includes statewide resources and recognisable branding.

> *With the Family Focused Recovery, they've put out a nice, glossy brochure and even though we don't do that a lot, I think there is power in having that and something to hand out to people, just that sort of acknowledgement. Even if it does sit on a shelf, we actually have something that is our product and our brand. (LHD)*

Various suggestions for a standard set of resources included: information brochures about the FCMHP; a framework document; information about the legal framework, including the NSW Mental Health Act and the Mental Health Tribunal; a webpage with links to relevant sources of information; a training package; and marketing and promotion material. Badging program-specific resources as FCMHP would assist in raising the profile of the program with families and carers, clinicians and other stakeholders.

6.3 Results: Service Effectiveness and Meeting Needs

In general, the FCMHPH is seen to be effective and to meet the needs of the carers who access it. Elements of effectiveness have included clear structures or guidelines, room for flexibility to allow for local practices and innovation and building partnerships.

The program has improved the lives and wellbeing of carers, helped carers to better understand mental illness and how to care for their loved one and themselves, and has helped to mend fractured relationships in families. The program has also contributed to changes in practice and culture in mental health services towards more inclusive, systemic approaches. Some participants believed the program has had an impact on emergency department presentations and hospitalisation.

Participants generally agreed that the quality of care specific to carers has improved with the program. Support provided to carers is also more consistently offered with carers' needs identified through routine intake procedures and support included in support plans. The program has raised awareness of carers' needs and their role in supporting consumers. According to many participants, there has been a shift from not only looking at 'what can I do for the consumer', to also considering 'what can I do for the carer'. Participants spoke about how the program has provided carers a voice and 'put carers on the map' (CMO).

There were some issues raised, however, around equity of access – geographically and for some minority groups and while there is evidence of practice and culture change, assumptions and poor understanding and support from some frontline clinical staff still remains a challenge.

Most carers appear to be well engaged in the program. Carers said the program gave then useful information and support and helped them to make connections with other cares and staff. Some also said being involved in the program had improved their mental health.

> *I'm 100% satisfied because the person who's supporting me one-on-one… she knows that I'm on challenging times. This time around once a week, and she'll text me. She will text me 'is this a good time to talk?' (carer interview)*

> *I have just been really, really pleased. I could only say positives about [the program]. (carer interview)*

Feedback from carers has indicated high family carer satisfaction with the program, including that program staff understand carer needs, are good at engaging carers and at working with complexity. Carers were surprised at the carer focus of the service, with many of them never having been offered support previously.

> *I'm very satisfied with the program, especially with the people that run the program, they're really professionals and they really took care of us. (carer interview)*

> *[One carer said to me] I was able to understand how she was feeling because I said something like, "What are you doing for yourself?" And she said, "No one's ever asked me that before." … It's always what can you do for the patient? (LHD)*

> *The service that I received from [the program] was absolutely essential and I simply wasn't getting that from any other service. (carer survey)*

Outcomes for families included: the know-how and confidence to navigate health and support systems and to advocate for themselves and their loved ones; knowledge about mental health, medications, etc. that assist them to care for their loved one; peer connections and support; and the 'permission', tools and space for self-care.

> *… for carers, too, having raised their profile and having people understand their lived experience, it's given them a lot of confidence to actually, now, navigate the mental health system in a different way. It's also empowered them to actually advocate for themselves and their person. (LHD)*

> *Carers are more empowered now to understand about their right and responsibility, and also learn about taking care of themselves, and that's important to me, it's very important that carers learn how to take care of themselves…. I think it has made carers better informed, less anxious, more efficient in finding help. (Statewide stakeholder)*

Program staff who had been involved with the Program over many years discussed how the Program had filled a gap for carers in which previously there was nothing for them.

> *I think if you look back from where we were before the Family Carer program, it's incredible what we've achieved as a program in terms of meeting the needs of families and carers who had absolutely virtually nothing before. (LHD)*

> *And I just remember being presented with carers that were so beyond distressed. We were consulting with carers, and they were so beyond distressed and almost traumatised because they hadn't received anything, no support, nothing. (LHD)*

> *I think it really does provide a high-quality approach to an unmet need, which we know we have got, which is the needs of carers and families are huge, significant and often unmet. (LHD)*

Many carers reported that the support and the connections they have made through the program have improved their mental health and wellbeing.

> *It certainly helps with my stress levels. It's good to have someone who's outside of our situation to talk to who can just listen and offer encouragement, or a lot of the time just listen and understand what you're saying. "Yes. That's very helpful". (carer interview)*

> *Oh, look, it lifted me because I just felt like I was in my own little world. …. To be able to just sit down and have a cup of tea or coffee, whatever, and a cake, … it's just a really good feeling to feel like you're a human being. (carer interview)*

Carers reported that the Program has helped to make them feel more hopeful and able to face the future. Carers also said that the program had helped to mend and improve relationships within families.

> *I find the program helped me to keep a positive attitude to the situation. (carer survey)*

> *I am very thankful to have been put in touch with this service - it is so nice to have a service that is there to support the support person in the cases of mental health. My [support worker] is just amazing and kind and puts everything into perspective and makes me believe that I can do this. (carer survey)*

> *Thanks to [the program], I was able to reconnect with my daughter. She has not returned home but we see each other regularly, and our relationship is much better these days. (carer survey)*

As well as increasing the capacity of carers to care for their loved ones through information education sessions, carer capacity is also built through attending case meetings, being more engaged with the treating team – overall being more actively involved in the consumer's care. Supporting the carer's wellbeing also allows them to better care for their loved ones.

Participants reported that the education and support offered to carers through the program may also be keeping people out of hospital.

> *I think for the system, it actually probably reduces bed days, admissions, costs, things like that. Because if the carer has got the skills to either identify early when someone is becoming really unwell to get sort of early intervention on that, or to reconnect them to clinical supports or to keep them going to clinical supports. (CMO)*

The program has improved carers' physical health and wellbeing, through focused education and information awareness sessions and initiatives. For example, one service has a monthly health focus on topics such as diabetes and skin cancer. Support staff have also assisted carers to engage or re-engage with a GP supporting the referral process. Support groups and other program forums that provide opportunities for peer connections with other carers have also improved carer health and wellbeing.

There were some issues raised around meeting needs, including access to the service in regional and remote areas. Participants reported some issues with access and variance in service delivery with specific services offered on the program varying between CMOs and LHDs. Geographically, services are not available in all areas within LHDs, which presents access issues for some carers, especially those in rural or remote LHDs with large geographical coverage.

Some LHDs are increasing access through telehealth however this is not seen as being as effective at engaging or supporting carers as face-to-face services. Conversely, during COVID lockdowns, online support has been necessary and carers in areas where this option has been limited or unavailable have received lower levels or no support. There also appear to be differences between rural and metropolitan areas regarding the acceptance of telehealth and online technologies:

> *I don't know if it is a thing, but from what I've heard and observed, in the city, we're more used to being individual, isolated, happy to get on FaceTime, whatever. But for a lot of communities, that's just not a normal thing still; it's, "No, you don't get on screen. (CMO)*

There are also issues of limited support services to which to refer people in rural and remote areas which limits options of supports available compared to better resourced areas.

> *So unfortunately all of our service, all of our area isn't serviced specifically. So yeah. So lots of people either having to do in-reach into [large regional town], or telehealth, those types of services. (LHD)*

There was feedback in the carer survey regarding the loss of access to the program in NSW border areas that are now managed by the Victorian Department of Health. Carers commented that they were unsure about what service they would be able to access.

I recently was told I can no longer use the services provided by [org name] as [our area] is managed by the Victorian health department. This is leaving a huge gap in the support available to myself and many other carers in the [my] area. (carer survey)

[Program] is a great service. Although now it is out of reach to me. Despite being in NSW. (carer survey)

6.3.1 Culture change

An important finding was that the program has contributed to changes in practice and culture within mental health services. Participants reported that clinicians are becoming more aware of the importance of carers in supporting consumers and some clinicians now see carers as a resource they can draw on.

I have seen a real shift in the inclusion of families and carers in communication, let's say just from inpatient settings, and from mental health health-based services. I've seen inclusion of families and carers in support plans. I think there is a real shift around the value of lived experience now, that I don't think historically I ever saw in program design and things like that. (LHD)

I think there is access to more support and different ways to access and engage with that support. … I think it's really helped to build on what I feel like I see across many of the community and health sectors is that family inclusive kind of model. It's really recognizing that this is not like anyone's journey within healthcare or within mental health, it's not a solo journey. (CMO)

Participants reported that there are still some challenges with getting support for the program from some frontline clinicians. They reported that some clinicians do not really understand the importance of the role of carers in consumer recovery. Some underplayed the programs activities, for example, seeing support groups as “knitting clubs” rather than as useful forums for peer support and education. Participants reported that some carers who might have consumers accessing LHD services, did not have access to the program as the clinician does not remember or want to refer the carer.

I think the other thing as far as for the service providers or healthcare system, if we didn't have these programs entrenched within our organisations, the families would fall off the radar. I could promise you that 100%. In fact, we know that there are still big pockets where the families or the carers aren't considered, because there aren't enough of us within the Family and Carer Program to ensure that it's always on everybody's radar. (CMO)

Every time they're talking about a consumer, what about the carer? What about the family? What's happening there? We can't be everything to everyone, so we have to rely on some of the champions that would be within our service that do work family-inclusively to model that for their colleagues. (LHD)

According to participants, there is still some work to do to embed the idea of clinicians seeing carers as an asset. Many clinicians still consider carers from a deficit base – thinking about how they can support the carer's plight or burden, i.e. thinking 'what can we do to help them?', rather than seeing carers as an asset and asking 'what can the carer do for us and the consumer?'.

> *Well, they have a different focus; they're providing a clinical service to a consumer and why would you talk to the family? And our response is you're missing three quarters of the consumer's life if you don't talk to the family. (LHD)*

The presence of family workers has helped to change the culture relating to family inclusive services, raising the profile of both the program and the benefits of peer and family workers. Some participants discussed the importance of the continuing work in this aspect of the program.

> *I think when I started in the role, we were trying to build that rationale for why we should include family and carers, and I think we've done that. I think that's something they still achieved, but clinicians still don't have the confidence of still believing in their own skills to do the work sometimes. And a lot of the questions that they ask are really tricky. Very intricate and intimate details of family life that you have to sort through. It's quite hard to do it. So I think there's still that role for coaching and mentoring services through those really difficult questions. And that's probably where we're at now, how do we take that next step forward? (LHD)*

Some program staff discussed the difficulties in overcoming barriers to culture change that may come from the health service and specific policies.

> *So we talk to mental health, and then mental health with domestic violence and more policies that say, "Oh, we can't work with someone that's a DV perpetrator." So it's really hard and I really want to see that integration of care happen, that collaborative practice where we're all heading that same way. But sometimes I'm a bit of a sole flag flyer incidentally. (LHD)*

> *I think the designated carer has probably made it that little bit more difficult for staff as far as navigating. We run training to help people to navigate around that. But you'll often find that they are a little bit worried about doing the wrong thing and who they are allowed to talk to, and that kind of thing.(LHD)*

Working through these issues can provide an opportunity for change on how worker and clinicians in the mental health system interact with carers.

6.3.2 Family inclusive services

Participants reported that the program has supported an increase in family and carer involvement in the care of their loved ones. A growing recognition that family and carers are partners in care, that carers have a right to be involved and that their involvement adds value have contributed to this increase in participation.

The program offers one on one support and group training aimed at helping carers understand their rights and support their involvement in the care of their loved one.

> *The one-to-one support, I think helps people understand their rights as a carer to learn what questions to ask, when they're with clinicians. To know that they can have a right to be involved with discharge planning and care plans and things like that. (CMO)*

Some carers said that their involvement in the program has given them the confidence and the information to speak up and advocate for their loved ones in other services.

> *The other thing that I found, too, was sometimes it gave me a bit more backbone. … Because it's really easy just to get pushed around by the medical staff. …. So I think having gone to the [program] has given me a bit, that's what I mean by a backbone. Going, "No, that's not right." And when [name] was in rehab, I've gone, "No, we need to do this and this." (carer interview)*

The program has embedded the inclusion of family and carers through building participation processes into practice. Some examples include: family meetings; needs assessment processes that include carer needs; and the inclusion of families and carers in support plans.

Most carers reported that the program itself considers their family and the support that is given to the carer has a positive impact on their family.

> *It seems as if they care about our family. Supporting and understanding my family situation. (carer interview)*

> *The program has helped our family to repair our relationships. (carer survey)*

Some carers felt that there were opportunities to involve the family more. Aboriginal and Torres Strait Islander and CALD carers, in particular, might benefit from the involvement of more extended family in the program.

> *I thought it would support our family as a whole, to cope better as a family but it's only focused on doing individual counselling for each family member, not working with the family as a whole, working on family goals and family communication - it's not helpful at all. (carer survey)*

> *It would be good if we could invite a family member to the workshops even if they are not associated with the organisation that I am. (carer survey)*

According to LHD and CMO participants, carers are now 'at the table' (LHD) rather than 'on the periphery'.

> *I see lots more carers being fully involved … from the assessment to the discharge of the person that they care for. (LHD)*

There is a stronger recognition of the importance of carers in a holistic approach to working with consumers.

> *It's the whole family that we see. …. we look at the whole context. I think our needs assessment helps with that process of a holistic look at the whole family. (CMO)*

Carer participation is important to carers and consumers, and can be very helpful to the clinician. The program has helped services and clinicians to recognise that if carers know what is happening in the clinical and support setting that they can ensure continuality of care at home.

> *... being included in that care, and certainly included in what's happening in discharge process is of paramount importance to the carer, so that they can continue to care for the person in the best possible way. (LHD)*

As discussed in the previous sub-section, there could be further opportunities to draw on the carers in the program to build capacity in LHDs.

6.3.3 Participation in program and service delivery

Participation of carers in program design and implementation is becoming more evident in many LHD and CMO services. Though not as well spread or embedded as inclusion as the individual case plan or treatment level, some LHDs and CMO services have structures to engage carers in service and program design and in governance and advisory roles. Some services also have Carer Peer Workers working within the program.

> *I love the fact that it's got so much participant voice in it, and that we are able to include carers in the design of our education and training sessions, in our meetings, to help steer us and make sure that we're on the right track. (CMO)*

Many of these roles have a co-design component where carers work directly with clinicians to design programs and education and promotion resources. In one LHD, carers are supported by the program, working together with program staff and clinicians to develop processes to improve family inclusive practices within the program and the services the program supports.

> *We've got the family carer action group, which we've set up, which is clinicians and family care participants together, sort of working on initiatives to improve family inclusive practice and looking at gaps and how we can be doing things more in a co-design sort of way. (LHD)*

There appears to be opportunities for increased participation in the program itself. Interviews and surveys showed little evidence of carers being involved in the governance of the program services at the local level. There was some discontent with service delivery in some services and a few carers felt their concerns were not being heard by the service or the LHD. Feedback was received in a carer survey and interview that as a result of changes that

had been made by the organisation to the program delivery they would be discontinuing their participation.

Some carers reported that there was a lack of known feedback mechanisms and that carers did not always get a positive response to feedback and complaints. Increased participation in governance and other quality improvement mechanisms, and more opportunities for carers to provide feedback will increase carer ownership of the program and invariably improve service delivery.

Systems change more widely

Program processes and initiatives where clinicians have worked alongside carers have had a wider reach than the program itself. Participants reported that the experience of working together with carers is increasing co-design and carer influence in other health programs.

> *… we have a much better grasp on collaboration and co-design when we're implementing new services, and when we're designing new healthcare facilities, and all sorts of things. Our mental health carers are involved in a whole range of co-design type activities, from brochures, which we've done one for the emergency department, for example, how to navigate the emergency department as a carer or a consumer of mental health service. (LHD)*

However, some participants also felt that there was still room for improvement in regards to carer inclusion.

> *And just that whole regular contact, that really clear delineation of who's doing what but how do we all work together to support that? And then part of me thinks and where's the carers in that? (Carer interview)*

Some carers who participated in interviews have been involved in systems change advocacy, others would like to be more involved. Most carers felt that there was much more to do. The experience of many carers was that the system is all but broken. Many gave examples of where the systems had failed them and their loved ones and whilst the program is assisting some carers to better negotiate the system, many carers are still experiencing frustration.

Some of issues included: lack of services (especially in rural areas), early discharge from services, poor follow up after discharge, disregard of carers and carers' experiences, carers afraid to speak up for fear of repercussion to their loved one, unsuitable environments for people experiencing mental health symptoms (e.g. ED waiting rooms), poor communication (e.g. use of jargon and acronyms) so that the carer struggles to understand what is going on.

> *I can't really say that I'm impressed with the system - there are pockets occasionally that give you a positive outlook - but it's a system that has a long, long way to go. (carer survey)*

> *The system failed terribly. It was absolutely terrible, we relied on our own resources to get him medical attention. (carer interview)*

And community health team, yes that fell flat on its face. He'd come out of hospital for the first five minutes they come and see you and, "Everything okay?" And then you don't see them, they just disappear off the face of the earth like, "Oh well, he's all right." (carer interview)

Well, I've not been critical of them. I just think sometimes they opt for an easy path, and it's not in the best interest of their patient. (carer interview)

Information and support from the program has helped carers to negotiate the system.

I still don't know everything, but I just feel that I know a whole lot more than what I did when I first started on this journey over 10 years ago. (carer interview)

Some carers would like the program to provide more support to negotiate the mental health and wider systems. Some carers had issues with NDIS support and others would like assistance from the program to apply to NDIS. One carer spoke about the difficulties negotiating the social security system and suggested that the program could perhaps help carers to do this.

Valuing carer participation

The increased participation of carers, at individual and process levels, has increased the value and respect clinicians and other people in mental health and support services have for carers. Participants spoke about a significant 'shift' to valuing lived experience. Value and respect were apparent in the recruitment of peer carer workers, the remuneration of carers in advisory and other roles, and the increasing propensity of clinicians to ask for and involve the carer in case planning.

The value of the lived experience I think is, of carers, is probably now much more forefront in people's mind in our health district in particular, because we have done quite a bit of work in that area. … clinicians are actually starting to see that families and carers have really important information and that they have a really valuable contribution to the life of the person that they care for. (LHD)

And I think we've seen a real uptake of the importance of lived experience in the workforce and so I think for me, that's invaluable. (CMO)

Most carers felt that the value of the program itself was the way they valued carers and the caring role. Most carers felt that the carers' role was valued by the program and that their own perceptions of their importance and self-worth had increased as a result of their participation in the program.

[My support worker] shows me self-worth. (carer survey)

Not only are you given practical information to assist in your caring role but they also stress how important YOU are. (carer survey)

So it's the carer, the carer's the person that controls all this, organises the schedules and looks after. And actually it's the recovery, without the carer a lot of

these people just end up on the street. We just can't underestimate the value of the carer. (carer interview)

Carers appreciated the carer centric focus of the program which for many was the first time they felt they had been given an opportunity (and given themselves permission) to focus on their own needs.

He's getting help. My help is the Carers Program. (carer interview)

Really, I tip my hat on them, the way they care for the carer. They always say look after yourself… have a few minutes for yourself, that sort of thing, which is really good. (carer interview)

And that it's a forum that's about you, not about all the people that you care for. (carer interview)

In particular, carers felt that the program has helped them to focus more on their own health and well being.

I didn't even realise that I need to do the self-care. You know self-care? That's the last few months, the last few months, that's the only time … it's like the penny dropped. Oh my God, and [the program worker] goes you really have to look after yourself... sorry, how can you provide something that if your bucket is empty, how could you water other people. (carer interview)

Enablers

Supporting people to participate, educating carers on their rights to participation, executive support, wider mental health reform and breaking down stigma are examples of processes that have contributed to carer inclusion.

The program has given carers confidence, support and information required to advocate for their loved ones. This confidence, new knowledge and experience advocating for or with their loved one could also assist carers to advocate at a systemic level. Program staff discussed taking a proactive approach to including carers with lived experience in their program:

And we're also being very encouraging to see if we can get those carer advocates to be someone with a lived experience of caring themselves. So it's nice to have that lived peer experience in there as well. (CMO)

Once carers have the confidence and knowledge one of the biggest enablers for carers to be able to participate was having some respite or support for their loved one to give them the time and the space for participation.

While NDIS and aged care support has freed some carers up to be more involved in the program and in carer advocacy work, most carers still find that their caring responsibilities makes regular engagement in any activities difficult. Some carers said that the fluctuating

nature of mental illness made it difficult to commit. An understanding that carers might not always be able to attend meetings in person would free up carers to participate in governance processes.

Educating carers on their rights and supporting carers to participate

The program provides education to families and carers on their rights to participate in the care of their loved one. The program also provides strategies and direct support to carers to facilitate participation. For example, they might attend meetings with the carer as the carer's support person.

> *We promote a carer charter of rights, I think on the NSW Health website, it talks about what the carer rights are. I think we do try to encourage people to make sure that they're aware of that and what they can do. (CMO)*

Executive support was seen as an important element of success. Participants reported that in areas where the executive really understood, believed in or 'championed' carer participation, it was much more embedded in service delivery. Executive support also facilitated carer inclusion in governance and accountability processes (e.g. KPIs).

> *Well, I would say that that role [of family and carers] owns that part of the carer participation, that it really has to drive it. It's something that this district, well the mental health service, and it comes from leadership at the top. Values that and wants to ... We put that into our strategic directions. We've got some things here, where we're trying to do genuine participation, building in frameworks, that kind of thing. It's part of this role to build it and grow. (LHD)*

Increasing lived experience participation, of both consumers and carers, is part of wider mental health reform. Consumer and carer inclusion are legislated through NSW the Mental Health Act and are included in Federal and State policy directives. This reform agenda has driven the inclusion of carer participation in mental health services and has continued to contribute to inclusion processes and programs (such as this one) that are changing attitudes and culture.

Breaking down stigma

One of the most important factors to ongoing increases and support for carer participation is carer participation itself. Carers who have been supported through the program have added value through their participation. Carer participation has also challenged assumptions and pre-conceived ideas about carers which then ease the way for increased carer participation.

Carers themselves might have pre-conceived ideas about mental illness and the clinical environment. Carers often had feelings of guilt and shame and thought that it was up to them to fix everything. Many carers found it difficult to trust others and open up due to previous experiences of stigma with family friends and staff within the mental health system.

> *This is all very new for me, reaching out for help, because I've been, "This is my problem. I will do this on my own." So I self-talk in my head, "Come on. You have to do this. You've got to do this." And just keep going forward. (carer interview)*

For the most part, carers found the program services non-judgmental and accepting and often a point of difference from their experiences in other services or in personal relationships.

Program staff and other stakeholders also reported that the program was breaking down some of the stigma and fear carers might have about mental health and the mental health system, helping carers to feel safe, comfortable and welcome in mental health spaces.

> *It's reframing the ward, the hospital ward as a safe place to be, not a place that you go because something bad has happened, and that it should be an inviting and welcoming place, and that people should be able to form better, closer relationships. (LHD)*

Challenges to carer inclusion

While participants reported that there have been significant increases in carer inclusion, there is some way to go before carer inclusion is fully embedded in services. There is variance between services and also within services with some clinicians more likely to support carer participation than others. According to participants, some clinicians continue to demonstrate resistance or ambiguity to working with carers. They report that carers are being excluded from participation by clinicians that forget or do not think to tell the carer about the program or actively decide the program is not for the carer.

> *Clinicians are so totally unaware of what's around the patient. They forget. They just see the patient in front of them, and they forget that that patient actually belongs to somebody, that has a family, and they've got other people around them. … it's often the psychiatrists that are very dismissive about the family, which is a shame really, but they often are dismissive. (LHD)*

Carers spoke about how they felt invisible, irrelevant or an annoyance to mental health service providers with their input often not sought or actively ignored. Carers also gave examples of support for carer participation in mental health system.

> *I've been told I'm a pain in the arse … "Your mum's a pain in the arse, you know that?" … and then the social worker sent me a message and she said, "I wish I had a mum like you." She says, "You don't give up" (carer interview)*

> *It's like you don't exist. You're not the important person. They're important because they're in a paid position. (carer interview)*

The program itself is helping to change clinician attitudes towards carer inclusion through educating clinicians on the importance and value of carer inclusion.

> *… there are some people who come into our service, perhaps not understand what a family-focused recovery framework looks like. Then, not actually having the skills to do that, but they start to develop some of those conversations, because our family and carer support workers are there all the time. (LHD)*

Tensions between consumer and carer perspectives

According to participants, one of the reasons cited by clinicians for their opposition to carer participation is that it might undermine the consumer's right to privacy or free choice. Participants reported that whilst there are tensions between the rights of carers and consumers, both have a legal and a moral right to participate. According to participants, family and carers also often have a caring role whether the consumer recognises them as carers or not. If carers are excluded from participating in the consumer's care when the consumer is in hospital, it can be very difficult for carers to provide a continuity of care on discharge back into their care.

Participants reported that sometimes when a consumer is unwell they might refuse the inclusion of a family member who has a primary role in their care. Conversely, sometimes an anxious carer, used to providing a lot of support for their loved one, might become overprotective and deny their loved one the right to make their own choices to their capacity. Participants also reported that family relationships are often fractious and there might be long-term or inter-generational trauma in the family that needs to be acknowledged and addressed before consumers and carers can feel safe working together.

Some carers said that their loved one did not believe that they are unwell or they do not recognise the carer as their carer. For a few, participation in the program is something they have kept secret from their loved one(s) or they feel guilty about attending.

> *Well, it just makes it difficult to have conversations with her about certain things. Because she just doesn't acknowledge that she's unwell. (carer interview)*

> *The program is helpful but I have frustrations with the system which doesn't involve me in my daughter's diagnosis or medications because she did not nominate me as her carer even though I am her primary carer. I wish [the program] had more power to interfere on my behalf as keeping me in the dark does not help my daughter. (carer survey)*

Some carers said that services working with their loved ones have shared information that they would have preferred their loved ones did not have. In some circumstances this has caused rifts within family relationships and also made carers wary about providing information to service providers from their perspective as a carer just in case it gets back to their person.

> *One of the things that I find there and this came out yesterday, quite obvious with this group, is the privacy thing. So if I have an issue, for example, if I didn't think my son was doing too well I would send a message to the [the mental health service] saying, "Look, this is what I'm finding, can you just work it into the conversation?" … And then the next thing, my son would ring me up and he'd say, "What did you tell them that for?" … I just don't tell them anything anymore because the fear for the repercussions from him. (carer interview)*

6.3.4 Elements of effectiveness

Participants cited a number of strategies, processes and structures that were seen as enablers or elements the drive the success or effectiveness of the program. Of particular note were program structure, flexibility and partnerships.

Program structure

Most carers found that the program structure which offers a combination of groups, one on one support and education forums provided the range of support they needed.

Most carers really liked **group forums and events** which gave them an opportunity to connect with other carers. Carers reported that groups gave them connections, purpose, validity, information and acknowledgement. For some people just having 'a cuppa' and making connections with other people who understood and did not judge was important. For others the purpose or activity of the group also had to be meaningful to them.

> *I haven't had a social life since I moved here. I've had no social life for 12 years. … So I have become very much a hermit. And I was aware that I was losing my self-identity. And that was where the writers group [as part of the program] was really good for me because it got me out to meet other people who are also carers of people with mental health issues. … It was always an opportunity for me to go out into public and a reason to put a bra on, a reason to brush my hair, a reason to put my teeth in. Whatever it was. It gave me a purpose. (carer interview)*

> *[I like] The connection with other carers to help you deal with the ups and downs of the caring occupation. (carer survey)*

Program staff reflected the changes observed in carers as they access the support they needed.

> *I think that when you talk to the carers now, they say the transformation is huge for them in terms of being understood, being able to access services, being able to be referred to support programs, support groups, education, resources that are available in terms of brochures and websites, all sorts of things that they have access to. So I think that's been quite transformational since the beginning of the program. (CMO)*

Carers reported that making connections with other carers improved people's mental health and wellbeing. Carers spoke about encouragement, support, peer learning and feeling less isolated.

> *The friendships, support and encouragement is beneficial. (carer survey)*

> *I find connecting regularly with other carers very beneficial to my well-being. (carer survey)*

Most carers found sharing life experiences helpful and validating. Many carers said they liked to hear they were not alone and found that they could learn from other people's responses to similar situations. Some carers, however, found talking about their own story and hearing the stories of others emotionally draining.

> *But I do find going to support group meetings I only go to occasionally, because I find that I come home, … I can come back worse off than I was before. (carer interview)*

Many carers also saw the group activities and events as a form of **respite or 'time-out'** to spend with other people who understood and accepted them as they were. Some services had offered overnight events which carers hoped would be reinstated when COVID allowed.

> *The time out provided by well-being activities is also great. (carer survey)*

> *Yeah, well they do different things. So we want and had a morning tea, went to the art gallery. I just look at it all as escapism from my horrible life. … Yes, it's good for me, for escape. (carer interview)*

Carers spoke about **education sessions** that were offered. These included education about mental health conditions and treatment, mental health and other relevant systems and referral processes, workshops that help the carers to care for themselves and strategies to manage difficult situations (e.g. grief and loss workshop). Many carers engaged in and appreciated the education sessions.

> *[The program] has been a great help to me and helped me understand my wife's condition better and to help her more. (carer survey)*

> *They had a day where they had all different speakers on which was very interesting. (carer interview)*

Many carers found that the option of **one-to-one support** helped to effectively meet their needs, especially when they were experiencing a crisis. Some carers were supported on a regular basis by program support workers. Support was often an informal chat over coffee or a phone call. Support offered was usually a supportive ear and help to workshop some strategies. One on one support could also include practical support including financial assistance or referral. Often, carers did not partake in the one-to-one support but liked a regular 'check-in' phone call and felt reassured knowing the option was there if needed.

> *Meeting with a support worker is a welcomed debrief. (carer survey)*

> *I come away from those experiences, whether it's coffee at the coffee shop with [support worker] or even a Zoom meeting with her … I feel re-energized and... For want of a better expression, I do feel re-energized and I feel like, yep, I can do this, I feel more in control. (carer interview)*

I've really appreciated being part of it and probably mostly as a safety net, knowing that if it all becomes too much, there's someone there I can talk to. (carer interview)

Some carer participants expressed a view that the support offered was infrequent, untimely or inadequate for the carer's needs. It was noted that not all programs offered one-to-one support, and declines in one-to-one support have increased with COVID in some services. How the one-to-one support was offered also differed between services. While some services would regularly check in with carers, at least one service left the onus on the carer to contact the service if they required assistance. This raised concerns about carers whose circumstances might make initiating the contact difficult or impossible.

At this stage I would dearly love some support, but don't get it even when reaching out, they forget or just don't bother getting back to you. I asked the support worker who emails me would please contact me as I was really struggling... that was 3 plus months ago. (carer survey)

When contact was made (by phone) it was very good and offering all sorts of help but it took three weeks after the incident that [was traumatic]. During that time we were desperate emotionally and very depressed as a family. I feel that it would have been more helpful and positive for us to have that support at the time of the trauma. (carer survey)

Due to funding cuts and restricted travel my support was extremely limited- support only there very infrequently. (carer survey)

Program staff also discussed the value of education and training provided by the program and the need to have a range of education options and flexibility in delivery to reach different types of carers at different points in their journey.

It's hard to say how much of it can be done by CMO and how much of it has to be done sitting one-on-one with someone and talking through their own personal experiences. It's tricky to pull those two things out. There's a need for both. (CMO)

I don't know if everybody's able to access it. I think there's some problems with finding ways of delivering information to families that they can access. Families, I think are increasingly busy, and I find it difficult to set aside time to attend training. It can be hard, I think, for families to find that time priority as well. (CMO)

LHD and CMO participants described the use of frameworks to ensure consistency of service. Examples included: the incorporation of carers' needs in consumer intake processes, use of the five point plan, triage processes for carers, development and use of operations manuals and support plans. Increased formalisation of procedure brought about by the program has helped services to be more targeted in assisting carers and families.

For us, I think it really has helped shape us and get us back on track, and get us away from just being about having a cup of tea and a biscuit with somebody. To actually helping them with real issues in their life. (CMO)

There may be lack of consistency and/or poor communication as to how some tools were applied. A few carers referred to the Carers Star, with some saying that the service working with them to set goals has given them purpose and demonstrated the importance of the carer role. However, other carers have had different experiences. One carer felt that the Carers Star was a tick box exercise for collecting statistics and another said that there were completed Carers Star documents in their file which they did not recall contributing to.

I love [the Carers Star] because it's actually a gauge where I'm at, at the moment, and it's actually kept reminding me I haven't done that ... You're setting your own goals and you're looking at your own recovery. … I like the progress. (carer interview)

The Carers Star was done once, with me present, but the support plan part of it wasn't filled in. The same went for the next time it was done, but this time it was done without my knowledge. (carer interview)

Program staff reiterated the dichotomy of views regarding the Carers Star in that it can seem like a pointless box ticking exercise for some but that it was also a positive change in the way carers were assessed.

The feedback we got from carers at the time was why am I being treated like a patient of a mental health service of filling in a DAS, and it's right. It's like there's a big assumption around that rather than looking at holistically around someone's wellbeing and their functioning in their normal roles. So it was a really good thing that they switched that. (CMO)

Because I've seen it when I've worked with consumers: "Oh, tick, tick, tick, tick." I mean, it meets a box, it ticks a KPI, but really, is it meaningful? And is there a better way, not just in family carers but other services… that it could be streamlined, because it sometimes can become a barrier in a relationship. (CMO)

Other elements of success for carers were **caring, well informed workers** and access to other services.

The workers are professional, knowledgeable and caring. (carer survey)

I've talked to [the support worker] quite a few times and found that very supportive. (carer interview)

I love the way they have that connection, a personal connection with the carer that actually pre-empt what we need. (carer interview)

It appears however, that not all carers were happy with the professionalism and/or the work practices of program staff. A small number of carers cited examples of not feeling properly

supported and a few said that their involvement in the program has been harmful to their mental health and wellbeing. Some carers recommended mandatory training for staff in Recovery Orientation, and Trauma Informed Practice to ensure that the program does not inadvertently cause harm.

> *I have strongly supported the [program] and recommended them to fellow carers. This is a very sad day for me to state they have made me feel the opposite way and wiped out any beneficial feelings. (carer survey)*

To ensure equity of access, wider **promotion of the program** might need to be considered. Many carers appeared to have heard about or been referred to the program by chance and many wished that they had heard about it earlier.

> *I have been a carer for most of my life. I am 52 and I have never been told about these groups until a friend told me. Why are we not told there is help when we are without loved ones at appointments or given information. (carer survey)*

> *It would have been very helpful if we had known about this service when our son was first incarcerated. (carer survey)*

> *It just fascinates me that there are these things that are here and maybe have been here for a while and I had no idea about. (carer interview)*

> *I'll start with it's been a really good learning experience because as someone who is a de facto carer for someone in my family with mental health, I didn't know that this program existed, and I've worked in mental health in the community sector. It baffles me I didn't know because it's such an incredible resource. (CMO)*

Some suggestions for more comprehensive promotion included: Information brochures given to each and every family when their loved one enters the hospital or forensic systems and that information is available in relevant services including in EDs, doctors surgery's, chemist's, police stations and any other places where carers may go for help.

Some carers reported that **inconsistencies in staffing and management structures** and staff turnover are affecting the number of front line staff available and face to face service provision.

> *Definitely in [rural area], worker to client ratios are huge. (carer interview)*

> *Because of staff structure problems. I'm not sure if the group will still exist. (carer survey)*

Staff turnover was also mentioned by program staff as an issue for program delivery.

> *The CMO, they're providing the education that's directed at families, that's the support groups is the one-on-one support. So all of that is fantastic. We've got a good partnership with our CMOs. But I think what's tricky about that relationship is the turnover of staff in the organisation. (LHD)*

Some carers said that they liked that there was access to specialist mental health services, such as psychology, through the program. This has given carers access to services they might not have accessed previously. However, this was not available in every service with other carers suggesting this as a program enhancement.

> *And through [the program], for the first time ever, I've had the chance to speak to a psychologist, and that's been really good for me, too. Because I get to where I say how I feel, or how I think I look, "Maybe I've done this." Because it's only my family, and we're a very small family, who will say, "[Name], you were a great mom."... I think because of my circumstances, that I could continue speaking to her free of charge. And she's also helped me a great deal. (carer interview)*

> *It would be great if they had more reach into services like Child psychologists/ Psychiatrists, and programs that are really hard to get into at the moment, if you can get in at all. (carer survey)*

> *…on occasion, carers, themselves, sometimes need some more specialised interventions and support, whether it's counselling or whatever it might be. So sometimes we have to refer on to other CMOs as well. … so it's a bit like… I've got to re-tell my story to somebody else now. (LHD)*

Carers also spoke about the **value of having people with lived experience providing support services**. Cares found that they could relate better to workers with lived experience and that they felt more understood and less judged.

> *So this chick that I talk with, we had one-on-one with, and she's really cool because she can relate and she can say, "Oh, my son did..." And she will give an example. And I'm like, "Yeah. That's what I'm talking about." So that's really good for me to bounce off. (carer interview)*

> *The support worker has a lived experience of mental health and is very kind and non judgemental whilst also offering practical support. (carer survey)*

Flexible practices and processes

Flexibility and the space for local innovation appropriate to local conditions is also seen as an element of success. This has included the development of procedures and tools at the local level. Most services also offer a range of options to carers to allow a 'tailored' response to care.

> *They can take what works for them, and there are different options, whether they do like that support group kind of format or whether they more need that individual kind of support. Or, they're more just keen to understand more about what's going on, and they have that tailored response to the families. (LHD)*

Most carers preferred relaxed, informal approaches to services where they could access more or less support as their needs changed. Carers reported that more relaxed, informal environments and forums were conducive to making connection and sharing life experience.

As time goes on I need less support around the person I am caring for so have reduced the one:one meetings to 8 weeks. (carer survey)

Even if I don't take part in something, knowing that there's that option. … I know that [the support worker] is there and I can ring her if I want to. So it's knowing that that support's there as well as actually having the call. … is good. (carer interview)

Some carers said that the programs do not offer enough options or flexibility. Others suggested that the time that the support was offered was not suitable to their caring or work commitments or to when they might most need the support. Further, some carers wanted more options for where support took place, e.g. in the home or closer to home. This was particularly important to carers in rural and remote areas. Other carers wanted more options of education topics and support that suited their circumstances, the needs of their loved one or other considerations like culture.

Program staff discussed being proactive in regards to providing services guided by carers' needs.

I think the services that we're providing to families and carers are very guided around carer feedback. So we have carers provide feedback from events and groups that they attend, but we also do the yes survey. We also go off requests for events. And after COVID, the main request for support and services has actually been that real face-to-face connection, and self care. (CMO)

Flexibility on entry and exit to the program was also seen as an element of success though this varies between services. Some services have no time limit on access to programs. This has allowed flexibility for carers to dip in and out of the program which fits with fluctuations in their loved one's mental health and the needs of the carer.

I know that [the program] is available at any time should I feel the need to use it, and I may return to [service name] in the future if my situation changes and I feel that it is warranted. (carer survey)

There were concerns raised, however, about demand exceeding capacity when people become engaged and somewhat reliant on the program and may not exit when their needs may not be as pressing as new carers looking to access the program. Strategies used to address this included what one participant called 'soft leaving methods', for example a cessation of one-to-one support but continued engagement in social and information sharing/education events.

Equally, participants also reported being concerned that some carers might leave the program too early. Carers can have difficulty keeping a focus on when their loved one is unwell and this shift of focus and a corresponding lack of time can cause carers to disengage from the program when they perhaps need it most.

> *… what we find is that people are in crisis, if our people with lived experience are in crisis, then our carers are often in crisis. They often don't have the time or the energy to engage with the family and carer support worker, even though it would be a good thing to do. (LHD)*

There are significant differences in how long people can access the program depending on the service they are accessing. This creates inequities and some carers in services with end dates expressed anxiety about how they might cope once they could no longer access the service. Some more flexibility around exits is required to ensure people have the support they require. There was at least one example of an abrupt exit due to the death of their loved one when perhaps the person most needed extra support.

> *My time is up with [the Program] I don't know what will happen. (carer survey)*

> *My two years permitted on the program is just about ended. I think Covid is causing problems but I know I am in a much better place to deal with issues when they arise. I don't know that I am completely ready to go solo and would like to be able to reach out for help should I need it. (carer survey)*

> *There was a woman who cared for her sister for many, many years and they were very, very close and the sister died suddenly. The lady came to the morning tea and said, "I'm so happy to be at this morning tea. I really needed this support from this group because my dear sister passed away". … But she was very briefly told, "Well, she's dead now, you are out. Time's over, out. Goodbye." (carer interview)*

Being able to access and refer carers to the program in a timely manner often relies on the support given to clinicians to view patients as inclusive of their families:

> *So I think it works really well when clinicians are supported to be very recovery oriented, to see the person as a whole person and include their family naturally from the beginning. I think there's really good work being done with families in early intervention teams. But it's about the timing of engagement with families, I think, and oftentimes families are left to flounder for a long time before they get support. So I think it works really the best when you have that early engagement approach. (LHD)*

Partnerships

Strong collaboration and formalised partnerships between LHDs and CMOs have been essential to the program's success.

> *We've got really strong partnerships out there, our service makes a lot of referrals to our families and carers and they provide a really great service. (LHD)*

Most participants have found collaboration between LHDs useful and would like more opportunities to share local innovations, locally developed processes and tools. As program

staff have identified and built rapport with support services in the community, the program has increased access for carers to other services beyond the LHDs.

> *…there's been a lot of advocacy and lobbying and carers' rights, and I think the FCMHP, for me, just has that really comprehensive, holistic approach with the relationship with the local health district and then the CMO. (CMO)*

Some suggested that collaboration is somewhat thwarted by workload and competitive tendering environments. It was suggested that greater central coordination to support statewide collaboration to share tools and processes developed locally is required. One participant reported that there might need to be some more work done to engage LHD Community Mental Health services.

> *The community mental health services, I believe are a lot less well engaged with the family and carer program, interestingly enough. So actually, that would probably be a good area to explore because I'm not aware of a huge amount of engagement between community services and the Family and Carers Mental Health Program. They do tend to be focused on those people who require hospitalization and their families and carers. (Statewide Stakeholder)*

Some carers felt that there were some missed opportunities for partnerships between CMOs and LHDs to draw on carer expertise to improve mental health provision and carer participation within the LHDs.

6.3.5 Meeting the needs of marginalised and/or minority groups

Aboriginal and Torres Strait Islander people

Some participants reported that the program has not effectively engaged or met the needs of Aboriginal and Torres Strait Islander people, although some providers reported positive progress. Some thought this cohort may prefer specific Aboriginal and Torres Strait Islander services. Some suggested that more work needs to be done to build cultural competence and relationships with local Aboriginal and Torres Strait Islander people services and elders.

Participant suggestions for improvement to increase access to the program for Aboriginal and Torres Strait Islander people included recruiting Aboriginal and Torres Strait Islander peers to the program, providing extra resources to build partnerships with Aboriginal and Torres Strait Islander groups and build cultural capacity of program staff and other stakeholders.

Some areas have high Aboriginal populations compared to the national average (e.g. Western NSW, Mid North Coast and South Coast) and it was agreed these areas don’t always have an Aboriginal person to work with these populations. Where they do, Aboriginal carers tend to engage more with the service.

> *So we have [name] in that role and it's been very great to have Aboriginal person in that position. We have more Aboriginal carers now engaging with the service. (LHD)*

Culturally and linguistically diverse groups

CALD carers were largely happy with the program and grateful that they had access to the support. There appears to be a diversity of appropriate support for CALD groups depending on region. Some services find engagement with CALD groups more effective than their engagement with Aboriginal and Torres Strait Islander people. Other LHDs struggle engaging with both groups. Participants reported that access to appropriate CALD carer services is better in LHDs with larger CALD populations where the opportunities for partnerships with CALD services were more available in the community.

Strategies that have assisted services to engage with and support CALD carers are; partnerships with existing CALD services in the community, recruitment of CALD staff, including CALD peer workers to the program, and separate bilingual support groups. While there are some good initiatives for engaging and supporting CALD carers in some LHDs, there is variability. Even in LHDs where there are high numbers of CALD carers and support is relatively better, participants said that full access to the support the program can offer may not be available to all CALD carers, especially when language is a barrier.

> *… definitely, the service of the FCMHP are more effective for carer from English speaking [countries]. … They can easily access the service, in terms of, for CALD carers, apart from receiving psycho-education … they can't actually participate in the carer education that is run in English. (Statewide Stakeholder)*

The program has given CALD carers a forum to discuss mental illness and the challenges they face in their caring in ways they might not be able to with their family and friends due to cultural taboos around mental health. Some CALD carers still have concerns about sharing in the groups due to self-stigma.

> *There's a lot. It's taboo to even discuss. Right now, I don't feel comfortable of talking anything with regards to mental illness. Me myself, it's a barrier. Through the program, it actually educate me that it's okay, it's safe, and it's better to discuss than to hide it under the carpet, sweep it under the carpet. (carer interview)*

Young carers and male carers

While there are a number of initiatives underway to increase engagement, young carers and male carers are largely underrepresented in the program. There were a few examples of couples accessing services in the interview cohort when the person who they cared for was their child (including adult children). On the whole, however, the mother was more likely to access the service on their own even when the father was still in the picture.

When they do access the program, the support offered to young people and males is often not well tailored to their needs.

> *I think on the whole, the people ... well, people in our youth and family teams are very good at connecting with families. … I think that we don't do so well with young carers. … when our CMO here gets families or they're aware of young*

people, then they will dive into that and explore and see what support can be offered but I think on the whole, our young carers don't get as much as they could. (LHD)

The program tends to be focused on the biggest cohort of carers and that will mainly be parents and partners, and often the female partner or mother a little bit more frequently than the male. (Statewide stakeholder)

Initiatives to increase engagement and tailor appropriate support to young people and males include the employment of male carer peer workers, building relationships with organisations that work with these groups (e.g. school counsellors, youth centres) and running groups that are specific to these cohorts.

We've introduced a peer worker, which is the male worker. And he comes from a background of being a young carer. So he works with our program and he has brought such a different dimension to our program. So he works with the young people, and with male carers as well. So that's been great. (CMO)

Some participants also raised concerns about the need for strategies to engage what some called 'hidden carers'. These might include people with a caring role who do not see themselves as 'carers', carers who do not know about the program or carers who cannot access the program. One LHD has done some work on identifying 'hidden carers'.

We did a whole lot of work on hidden carers, the people who actually could use the program. They don't know about it. They don't know how to access it maybe. That they're working carers, maybe they're young carers. (CMO)

6.4 Effects of the COVID-19 pandemic

The COVID-19 pandemic has had a significant impact on families and carers and FCMHP providers. While some services reported a decrease in the number of referrals in the early stages of the pandemic, there is now an increase in referrals with families and carers presenting with even more complex needs.

If anything, we're seeing a bit of an upturn in carers coming through with changed needs. So things around obviously family pressures and finances and work and lockdown and family violence. (LHD)

While there have been some periods where restrictions eased and more normal operations were able to restart, the ongoing outbreaks and lockdowns, as well as a period of natural disasters, including floods, fires and the mouse plague, have prolonged the difficult circumstances and uncertainty that families and carers are experiencing.

I think also because there was a sense of hope at the start of the year [2021], or even a few months before, it's that sort of, 'We're normal. We're not.' and that has an impact. (CMO)

For all family members, it's been very trying. But …now there's just that uncertainty. (CMO)

Carers were reported to be increasingly anxious and distressed with a greater sense of isolation. They were impacted by being in their caring role 24/7 without any respite or wraparound services, as well as lack of face-to-face contact, potentially leaving them at home 'potentially in psychologically or emotionally, physically unsafe environments' (CMO).

There was also a fear among carers around presenting to health services such as hospital emergency departments. A further concern was the lack of a 'safe space' for carers to talk openly about their issues. Carers have also been impacted when inpatient facilities have been locked down and patient visits have not been allowed and there are no leave provisions for consumers.

…there was couple of months there, was around providing that support to families and carers where home wasn't actually safe, and being able to have those supports in place and safety plans. So that was something that we really focused on. (CMO)

We just tried to really be there. Our emotional support really increased during that time. It was massive. (CMO)

There have been positive learnings and outcomes from the adjustment to the pandemic conditions, and some innovations have been implemented that are seen as ongoing opportunities to enhance the program. The services demonstrated that they were able to be creative and flexible and respond quickly to the changing environment. This meant that the program continued to operate, albeit with the many changes which were implemented in response to the conditions imposed on both providers and carers.

I think it's made us think and be really flexible and adjust and, things that we've thought weren't possible are actually quite easily doable. (LHD)

Increasing use of the telephone and online technology to engage with carers, such as digital platforms for social events, education sessions, meetings, and the provision of links to additional resources, had the benefit of improving access opportunities for some carers. Issues such as remoteness, travel costs, work commitments, and being unable to be away from home had previously presented barriers to program involvement.

There are those carers that say, 'Hey, you know what? I actually can't leave home, so this works out so much better for me because there's no one here for my loved one'. (CMO)

Another benefit of moving services online was the opportunity to upskill carers' computer literacy, which also assisted them in accessing other online services, such as telehealth. In contrast, some carers were unable or reluctant to use or access technology for a range of reasons, including financial constraints and a lack of internet service availability in some regional and remote areas.

> *…in the city, we're more used to being individual, isolated, happy to get on FaceTime, whatever. …for a lot of communities, that's just not a normal thing still; it's, 'No, you don't get on screen.' So there's all those other contexts, and also looking at disadvantaged communities, that some carers that may not be able to afford an internet bill or to rack up an internet bill. Or some of the indigenous communities. (CMO)*

The pandemic has highlighted that the provision of face-to-face contact is an extremely valued and essential component of the program, providing many benefits to families and carers.

> *They have been offering online support groups and online education. Some people take it up, but it's had a huge swing or indent in that part of the program because it's not the same … to meet a bunch of strangers or a regular group online. … Because when you go to a support group, it's not just the sitting around, it's the coffee before, the tea afterwards, the bickies. It's a community thing. It's challenging to build that. (CMO)*

> *I think the challenges for carers were that those groups and things that were provided and the space that they had to join together, got them out of the house where they might be caring for their loved one there and so that break is not there for them. (CMO)*

The benefits of program staff being physically present have also been highlighted by the COVID-19 restrictions, including the opportunity to promote the program in the services; 'it helps to really keep it in people's minds' (LHD); and to access families and carers to alert them to the FCMHP.

> *So I think that that – once they are able to come back and do that face-to-face type stuff, that's where they really shine, and I think that's where they really were able to do a lot of really good work. (LHD)*

While the longer term impact of the pandemic is unknown at this time, it is clear that the need for increased mental health services will be ongoing and the FCMHP will need to be sufficiently resourced to meet the needs of families and carers and successfully achieve the program objectives.

> *And there's a whole range of reasons why these sort of programs are actually more critical than they were pre-COVID. (LHD)*

> *We see with this COVID thing, it really shows the great divide between those that have and those that don't have. And we see that in our carers. (LHD)*

7 Discussion

The FCMHP has two broad objectives - to increase the capacity of mental health services to work with families of clients with mental illness, and to decrease the stress and burden of families of clients with a mental illness.

The FCMHP partners deliver services aimed at achieving these broad objectives. The focus of LHDs is delivering educational activities aimed at increasing the skills and confidence of staff to embrace family inclusive principles. The focus of CMOs is providing community based education, individual and group support services for mental health carers. The JH&FMHN focusses its efforts across both areas. While there is significant overlap across the partners, there are also core differences.

This section synthesises and discusses the range of important findings that have emerged from this evaluation. A set of recommendations is also provided to support the ongoing delivery of FCMHP services.

7.1 A context for understanding FCMHP outcomes

There is an abundance of evidence to support the crucial role of carers in providing support for people with mental health illness.[39,40] NSW legislation explicitly recognises the important contribution that carers make and their need for support to continue in this role.[41] The establishment of the FCMHP in 2005 reflects the Ministry's commitment to supporting the role of mental health carers.

The FCMHP has been funded by the Ministry on a recurrent basis for several years, with this arrangement expected to continue. In this context, the evaluation did not aim to conduct a formal assessment of the program's historical performance. Rather, it sought to review the program's outcomes in the context of identifying opportunities to enhance its ongoing effectiveness. This is known as a 'formative' evaluation approach. It seeks to inform what is being evaluated to ensure there is a clear picture of how and why a program has produced particular results.[42]

In seeking to understand the outcomes of the FCMHP, it is also important to recognise that a wide range of internal and external factors have influenced the program at different points in time throughout its 15 year history. Importantly, the FCMHP is only one program that operates within a broader policy and service delivery environment. Support for carers in NSW is provided by a mixture of State and Commonwealth government agencies and

[39] Australian Government (2010) 'National Standards for Mental Health Services 2010', *National Mental Health Strategy*, pp. 1–60. Available at: http://www.ag.gov.au/cca.
[40] Mottaghipour, Y. and Bickerton, A. (2005) 'The Pyramid of Family Care: A framework for family involvement with adult mental health services', *Australian e-Journal for the Advancement of Mental Health*. Informa UK Limited, 4(3), pp. 210–217.
[41] New South Wales Parliament (2010) NSW Carers (Recognition) Act 2010 No 20.
[42] Patton MQ (2002) *Qualitative Research & Evaluation Methods, 3rd Edition*. SAGE Publications, Thousand Oaks, California.

funding streams. This is supported by a range of community-managed organisations and private enterprises that perform a variety of health service, community support, research and advocacy roles. An ongoing challenge for the FCMHP as a program is to adapt within this environment to ensure that it continues to play an effective role in supporting carers.

In these circumstances, impact can be assessed in terms of 'attribution' and 'contribution'. Attribution occurs when an intervention is shown to directly cause a desired outcome. In contrast, contribution occurs when and intervention is shown to help cause an observed outcome. For community programs, if there is sufficient evidence from multiple sources to develop a thorough understanding of a program, it may then be reasonable to conclude with confidence that a program has made a contribution to achieving a desired outcome[43]. Data from multiple internal and external sources were examined to develop a clear picture of the extent to which the FCMHP has achieved its objectives.

7.2 FCMHP: Key evaluation findings

The FCMHP evaluation examined data from numerous sources, including a significant volume of historical documentation. It has found that the services delivered in combination by CMOs, LHDs and the JHFMN have contributed significantly to increasing the capacity of mental health services to work with families of clients with mental illness. At the same time, the work of the program has directly led to a decrease in levels of stress and burden among carers and families of clients with a mental illness.

The program is now widely regarded as an important and successful initiative. It is well established within the mental health sector and recognised as having improved the lives of carers over many years. The evaluation has also identified a number of opportunities to enhance ongoing FCMHP services.

7.2.1 Family and carer level outcomes

A strong body of evidence emerged supporting the positive impact of the FCMHP for families and carers. Evidence of positive outcomes across the program was broad ranging. Most importantly, it included carers having a better understanding of the health system and therefore being more empowered to support their loved one, but also improved self-care skills and capacity to maintain their own health and well-being. Further, the program has contributed to improved family relationships and helped carers develop a better sense of their own value.

The inclusion of the Carers Star tool in 2018 was an important addition to the FCMHP MDS. Being able to routinely measure levels of carer well-being is an important mechanism for the ongoing monitoring and evaluation of FCMHP services. A longitudinal analysis of Carers Star data conducted for the evaluation identified improvements in levels of carer well-being over time, most noticeably in the 'Health' and 'The Caring role' domains.

[43] Almquist A. (2011). Attribution versus contribution, National Centre for Chronic Disease Prevention and Health Promotion.

Importantly, the contribution of the program to improving carer well-being captured by the Carers Star data was strongly supported by both the carer evaluation survey and stakeholder interviews. Carers reported improved personal mental health resulting from social connections made through the program, being understood by program staff, improved know-how and confidence to navigate the health system, and an overall improved sense of hope for the future.

The evaluation also identified areas where there is opportunity to improve FCMHP services. An analysis of the profile of carers highlighted that younger male carers are significantly under-represented across the program. The interview data confirmed a sense that the program is largely accessed by middle aged to older women.

The interview data also highlighted inconsistency regarding how effectively the program has engaged with Aboriginal and Torres Strait Islander people and CALD groups. Other areas with prospects to improve outcomes for families and carers include better promotion of the program, more carer involvement in program governance and design, and improved consistency across the state in the response to COVID-19 across the state.

Recommendations to enhance FCMHP outcomes at the families and carer level

1. Establish clear and transparent feedback mechanisms including training and program guidelines to encourage carer input and feedback on program design and practice;
2. Implement appropriate minimum training requirements for CMOs staff, including Trauma Informed Practice and group facilitation to ensure carers feel safe and included;
3. Develop strategies/guidelines/requirements for carers to be included in program and local CMO governance and quality improvement processes;
4. Develop strategies and consider minimum requirements to ensure all carers have access to the key elements of the program – i.e., personal support, peer support, peer connections, education.

7.2.2 Provider level outcomes

Provider level outcomes have been evaluated in terms of how efficiently the program's resources have been targeted and whether effective staffing structures and partnership arrangements have been established across the program.

The total funding envelope of the FCMHP largely determines the scope of practice for the program's services. Relevant funding agreements, SLAs and KPIs then provide a framework for services to determine their model of care, partnership and staffing arrangements.

Overall, the evaluation found that resources are being efficiently utilised both within and across the program. As expected, almost all providers felt that funding for the program is not sufficient to meet the level of demand for their services. While a formal needs analysis was beyond the scope of the evaluation, an analysis of the carer profile data indicates that there is clearly a level of unmet need for services, likely to be greatest in rural and regional areas. Further, inconsistencies in historical LHD funding arrangements have compounded inequities

in access to the program for some carers. Again, this is most evident in rural and regional areas.

Differences in models of care between LHDs emerged as a significant issue. As noted, some LHD coordinators spend considerable time delivering services to carers while others do not work directly with carers at all. While this flexibility allows LHDs to respond to their local environment, the current arrangements also seem to be strongly influenced by the personal preferences of LHD staff. While this issue was not explicitly raised as a concern by carers, other stakeholders suggested that greater consistency would result in a more strategic and coordinated approach across NSW. In particular, it would allow clinical need to be more easily identified, as well as more appropriately targeting services for groups such as CALD and Aboriginal and Torres Strait Islander people.

The scope of practice of CMO staff emerged as an issue of concern for some carers and program staff. Some carers and program staff felt that upskilling CMO staff to deliver clinical services such as counselling or family therapy would meet an important unmet need. Currently, CMO staff are largely employed in non-graduate roles that provide support work. Similarly, the majority of LHDs do not offer this level of clinical support. However, this change would require a significant policy shift for the program and have associated funding implications. Other program stakeholders felt strongly that it is not the role of CMOs to be delivering clinical services.

A related staffing issue concerns the increasingly important role of peer workers within the program. While it is recognised that carer inclusion has not yet been fully embedded in services, the capacity of the program to embrace this workforce is an important positive outcome for CMOs, LHDs and the JH&FMHN.

In contrast, it is also evident that there are very few identified positions for Aboriginal and Torres Strait Islander staff across the program. A number of important suggestions in this area were identified including recruiting Aboriginal and Torres Strait Islander peers to the program, providing extra resources to build partnerships with Aboriginal and Torres Strait Islander groups and building cultural capacity of program staff and other stakeholders.

Recommendations to enhance FCMHP outcomes at the provider level

5. Increase program funding to employ people with lived experience, males, Aboriginal and Torres Strait Islander and CALD people working in the program;
6. Develop strategies resources to ensure the program promotion, design and practice are appropriate for minority groups and others who are currently underrepresented in the program;
7. Ensure that carer peer workers are integrated into the staff profile of the FCMHP providers;
8. Provide additional funding to resource more flexible options for program delivery – e.g. after hours support and education activities, additional outreach support.

7.2.3 FCMHP: System level outcomes

At a system level, a number of important achievements of the program have emerged from the evaluation. Perhaps the most important is its significant contribution to embedding family inclusive principles across the mental health sector. Data from multiple sources confirmed that each of the program partners have contributed to this result. Evidence of improved adoption of family inclusive principles included: improved rates of carer participation in program design; greater acceptance of tailored family interventions; overall increased recognition of carers among clinicians; and greater engagement of carers in governance and advisory roles.

In relation to the current FCMHP structure, the evaluation found that it is appropriate and promotes effective and efficient service delivery. The majority of stakeholders felt that the current structure encourages family inclusive principles across the sector. Strong collaboration and formalised partnerships between LHDs and CMOs emerged as being essential to this element of the program's success. The coordinating role of the Ministry, including its management of the statewide FCMHP committee, are also crucial components of the program's successful structure.

Quantitative data highlighted the substantial overall reach of the program. More than 6,200 individual carers participated in more than 16,500 CMO service events over the most recent 27 month period for which data were available. Public mental health services were the largest referrer to CMOs suggesting that effective referral pathways operate between the two primary arms of the program.

A significant proportion of FCMHP efforts can be characterised as 'educational', 'informational' and 'awareness raising'. These activities aim to increase the confidence of mental health staff to work within a family and carer inclusive framework. This is particularly the case for LHDs where FCMHP coordinators may or may not provide any face-to-face services to carers.

Methodologically, it is challenging to assess the impact of this work. Often, there is a time lag between the activity and any demonstrable evidence of outcomes. In some cases, it may even be years before discernible changes in attitudes and behaviours become evident.[44] However, impact can be assessed by analysing available information from multiple sources and assessing the relative contribution of a set of activities within the broader environment.

In this case, data collected by LHD staff provide evidence of an ongoing program of supporting and information sharing activities being successfully undertaken across NSW LHDs over many years. Moreover, the interview data with stakeholders across the program support a finding that the efforts of LHD staff have significantly contributed to positive culture change across mental health services.

[44] Measuring health promotion impacts: A guide to impact evaluation in integrated health promotion. (2003). Victorian Government Department of Human Services.

Overall, the evaluation found that the FCMHP has made a significant system level contribution to increasing the skills and confidence of staff in mental health services to embrace family inclusive principles. An analysis of interview data also suggests that these positive system outcomes may occur more broadly with reductions in emergency department presentations and hospitalisation.

Recommendations to enhance FCMHP outcomes at the system level

9. Conduct a formal needs assessment of the FCMHP to quantify levels of unmet need;
10. The program logic be adopted as a resource for the FCMHP;
11. Ensure FCMHP staff undertake initiatives to develop an understanding of how to engage and service marginalised and/or minority groups;
12. Develop a standard suite of resources for the FCMHP, in co-design with carers, with a process for systematic review and update in place;
13. Review LHD data collection and reporting processes in consultation with the LHDs;
14. Utilise the program data collections to assess and further develop the program.

Appendix 1 FCMHP Minimum Data Set specification (V1.3) Description and order of items

Itemno.	Data item	Field header	Metadata definition	Cell content	Field size	Mandatory
1	**Program**	prog	The identifier for theFamily and Carer Mental Health Program.	Code set: 5 FCMHP	Char (1)	Y
2	**Team code**	team	A unique code for theindividual team or agency providing services. A team maybe a subset of a provider organisation and are usually geographically based.The team codes are program specific. Codes are assigned by the Ministry of Health.	Code set: Refer to Appendix A Example: AC401	Char (10)	Y
3	**Reporting yearquarter**	year_quarter	Specify the end dateof the reporting year and quarter.	year quarter Example: 20170331	'yyyymmdd' Char (8)	Y
4	**Carer code – Provider**	car-code	Provider carer code isunique within a team/agency. Individual Providers may use their own alphabetic, numeric or alphanumeric coding systems.	Example: A123456	Char (20)	Y
5	**Carer Statistical Linkage Key (SLK)**	slk	A key that enables two or more records belonging to the same individual to be brought together in a manner that protects the privacy of the individual. It is represented by acode consisting of the second, third and fifthcharacters of a person's family name,the second and third letters of the person'sgiven name, the day, month and year whenthe person was born and the sex of the person, concatenatedin	Example: ERAUS201119692 Where the family name is not known, the number '999" should be used in place of the missing letters. Where the given name is not known, the number '99" should be used in place of the missing letters. Where a name is not long enough to supply the requested letters, the number '2" should be used to reflect the missing letters. Where names	'XXXXXDDMMYYYYN' Char (14)	Y

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Itemno.	Data item	Field header	Metadata definition	Cell content	Field size	Mandatory
			that order. NOTE: SLK should beused in Carer Star.	contain non-alphabetic characters (e.g. apostrophes, hyphens), these characters should be ignored when counting the position of each character. The values for Sex are either 1 Male, 2 Female or 9 Not stated.		
5	**Carer Statistical Linkage Key (SLK)**	slk	A key that enables two or more records belonging to the same individual to be brought together in a manner that protects the privacy of the individual. It is represented by acode consisting of the second, third and fifthcharacters of a person's family name,the second and third letters of the person'sgiven name, the day, month and year whenthe person was born and the sex of the person, concatenatedin that order. NOTE: SLK should beused in Carer Star.	Example: ERAUS201119692 Where the family name is not known, the number '999" should be used in place of the missing letters. Where the given name is not known, the number '99" should be used in place of the missing letters. Where a name is not long enough to supply the requested letters, the number '2" should be used to reflect the missing letters. Where names contain non-alphabetic characters (e.g. apostrophes, hyphens), these characters should be ignored when counting the position of each character. The values for Sex are either 3 Male, 4 Female or 9 Not stated.	'XXXXXDDMMYYYYN' Char (14)	Y
6	**Date of Birth**	dob	The date of birth of the carer. The day, month and year whenthe person being provided services was born.	year month day	'yyyymmdd' Char (8)	Y
7	**Date of Birth Status**	dob_stat	An indication of whether any	Code set: 1 Estimated	Char (1)	Y

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Itemno.	Data item	Field header	Metadata definition	Cell content	Field size	Mandatory
			component of the person's Date of Birthwas estimated.	2 Not Estimated		
8	**Sex**	sex	The biological distinction between male and female, as represented by a code.	Code set: 1 Male 2 Female 9 Not stated	Char (1)	Y
9	**LGBTQIA**	LGBTQIA	Carer who identify as lesbian, gay, bisexual, transgender, queer orquestioning, intersex and asexual or allied.	Y Yes N No U Unknown/ Not stated	Char (1)	Y
10	**Aboriginal and Torres Strait IslanderOrigin (ATSI)**	atsi	Whether a person identifies as being of Aboriginal or TorresStrait Islander origin,as represented by a code.	Code set: 1 Aboriginal but not Torres Strait Islander origin 2 Torres Strait Islander but not Aboriginal origin 3 Both Aboriginaland Torres Strait Islander origin 4 Neither Aboriginal nor Torres Strait Islander origin 9 Not stated	Char (1)	Y
11	**Country of birth**	cob	The country in which the carer was born, as represented by a code.	Numeric 4-digit ABS code from the ABS Standard Australian Classification of Countries, (ABS cat. no. 1269.0, SACC 2016).	Char (4)	Y
12	**Preferred Language**	lang	The language most preferred by the carerfor communication, as represented by a code.	A numeric 4-digit ABS code using the ABS Australian Standard Classification of Languages (ABS cat. no. 1267.0, ASCL 2016).	Char (4)	Y
13	**Interpreter required**	int	Whether an interpreter is requiredby the carer.	Y or N	Char (1)	Y
14	**Suburb/town ofresidence**	suburb	The name of the geographical district, town or suburb wherethe carer usually resides.	Example: Liverpool	Char (50)	Y
15	**Postcode of residence**	pcode	The postcode of the carer's usual place ofresidence, provided by Australia Post. Postcodes for post office boxes or	Example: 2640	Char (4)	Y

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Itemno.	Data item	Field header	Metadata definition	Cell content	Field size	Mandatory
			other administrative centres should not be used.			
16	**Start date in Programwith current CMO**	start_date	The date the carer started in the current program with the current CMO	year month day	'yyyymmdd' Char (8)	Y
17	**Source of Referral**	refer_src		Code set: 1 Self 2 Family or Friend 3 Public MentalHealth Service 4. Public Health Service 5 GP 6 Other Private Health Service/Practitioner 7 CMO (Different Program Provider) 8 CMO (Same Program Provider) 9 Other 99 Unknown/not stated	Char (2)	Y
18	**Source of Referral(other)**	refer_src_oth		Example: Corrective Services	Char (200)	Mandatory if code 9 reported at item 17.
19	**Blank**					
20	**Blank**					
21	**Blank**					
22	**Blank**					
23	**Blank**					
24	**Blank**					
The following list (items 25-45) does not account for every minute of funded support. However, all minutes spent with the carer should be recorded under these items. Any activity provided by another organisation should not be recorded as hours of support delivered by the provider.						
25	**Number of minutesof individual carer support in 1.Information**	infoind_mins	Individual support: General correspondence, phone conversationfor information requests etc.	Example: 0015 is equivalent to 15 minutes	'NNNN' Char (4)	At least one of items 25 – 45 must have non-zero values.
26	**Number of minutesof individual carer support in 2.Advocacy**	adv_mins	Individual support: Advocacy provided on behalf of a single individual.	Example: 0030 is equivalent to 30 minutes	'NNNN' Char (4)	Y
27	**Number of minutesof individual carer support in 3.Emotional**	emo_mins	Individual support: Assist carers to buildresilience, capacity and interpersonal skills.	Example: 0060 is equivalent to 60 minutes	'NNNN' Char (4)	Y
28	**Number of minutesof**	eduind_mins	Individual support:	Example: 0120 is equivalent to 120	'NNNN' Char (4)	Y

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Itemno.	Data item	Field header	Metadata definition	Cell content	Field size	Mandatory
	individual carer support in 4.Education andTraining		Educate or facilitate carers to build knowledge and skills.	minutes		
29	**Number of minutesof individual carer support in 5.Referrals**	ref_mins	Individual support: Refer carer to anotherservice for further action.	Example: 0120 is equivalent to 120 minutes	'NNNN' Char (4)	Y
30	**Number of minutesof individual carer support in 6.travel**	travelca_mins	Individual support: Travel – Time used totravel with carer.	Example: 0060 is equivalent to 60 minutes	'NNNN' Char (4)	Y
31	**Number of minutesof individual carer support in 7.other**	oth_mins	Individual support: Support that does notfit into other categories.	Example: 0060 is equivalent to 60 minutes	'NNNN' Char (4)	Y
32	**Description of individual carersupport – 8.Other - specify**	other_specify	Individual support: A description of the other one on one individual carer support that does notfit into other categories.		Char (200)	Mandatory if non-zero value reported at item 31.
33	**Blank**					
34	**Blank**					
35	**Blank**					
36	**Blank**					
37	**Number of minutesof group activity in 9.Information**	infogrp_mins	Group support: Information session.	Example: 0120 is equivalent to 120 minutes	'NNNN' Char (4)	Y
38	**Number of minutesof group activity in 10. Education andTraining**	edugrp_mins	Group support: Educate or facilitatecarers in a group setting to build knowledge and skills.	Example: 0060 is equivalent to 60 minutes	'NNNN' Char (4)	Y
39	**Number of minutesof group activity in 11. support group**	supp_mins	Group support: Support group.	Example: 0060 is equivalent to 60 minutes	'NNNN' Char (4)	Y
40	**Blank**					
41	**Blank**					
42	**Blank**					
43	**Blank**					
44	**Number of minutesof indirect carer activity 12.Program admin**	admin_mins	Number of minutes ofsupport in carer administration (e.g. Making a booking or spending time to go through service options).	Example:0120 is equivalent to 120 mins	'NNNN' Char (4)	Y
45	**Number of minutes taken to**	travelst_mins	Travel - Time used totravel to	Example: 0030 is equivalent to 30	NNNN' Char (4)	y

Itemno.	Data item	Field header	Metadata definition	Cell content	Field size	Mandatory
	travel to andfrom Carer 13.Travel		and from carer to provide support.	minutes		
46	**Other services-Community Services**	ref_cs	Did the carer visit acommunity service (such as a women'shealth centre or a Community Health centre) during this period?	Y or N	Char (1)	Y
47	**Referrals to otherservices – Other**	ref_other	Was the carer referred to other services during thisperiod?	Y or N	Char (1)	Y
48	**Referrals to otherservices – Other - specify**	ref_other_spec	A description of the other services to which the carer havebeen referred during the period.	Example: Undefined NGO support services	Char (200)	Mandatory if Y reported at item 47.
List items 49 - 56 are the summary scores generated from the Carer Star outcome measure.						
49	**Carer Star Chart completed**	cs	Record whether a Carer Star measure has been completed during the quarter/ period. It is expectedthat a Carer Star will be completed every quarter.	Y or N	Char (1)	Y
50	**Reason for Carer Star not completed**	cs_n	A description of whyCarer Star was not completed.	Example: unregistered carer, carer refused	Char (200)	Mandatory if N reported at item 49
51	**Carer star - Health**	cs_h	Managing physicaland mental health; healthy lifestyle; doctors and other health services.	Code set: 1 Cause for concern 2 Getting help 3 No pressing concerns 4 Mostly OK 5 As good as it can be	Char (1)	Mandatory if Y reported at item 49
52	**Carer Star - TheCaring Role**	cs_tcr	Skills; understanding; practical caring; legal issues; planning ahead; communicating with professionals.	Code set: 1 Cause for concern 2 Getting help 3 No pressing concerns 4 Mostly OK 5 As good as it can be	Char (1)	Mandatory if Y reported at item 49
53	**Carer Star - Managing at home**	cs_mah	Day-to-day tasks andthe suitability of yourhome – or that of theperson you care for ifyou don't live with them.	Code set: 1 Cause for concern 2 Getting help 3 No pressing concerns 4 Mostly OK 5 As good as it can	Char (1)	Mandatory if Y reported at item 49

Itemno.	Data item	Field header	Metadata definition	Cell content	Field size	Mandatory
				be		
54	**Carer Star - Time foryourself**	cs_tfy	Social life; activities; breaks from hands-on caring.	Code set: 1 Cause for concern 2 Getting help 3 No pressing concerns 4 Mostly OK 5 As good as it can be	Char (1)	Mandatory if Y reported at item 49
55	**Carer Star - How youfeel**	cs_hyf	Feeling supported; dealing with anxiety orstress; managing any difficulties in a key relationship.	Code set: 1 Cause for concern 2 Getting help 3 No pressing concerns 4 Mostly OK 5 As good as it can be	Char (1)	Mandatory if Y reported at item 49
56	**Carer Star - Finances**	cs_f	Benefits; debts; managing money;legal issues.	Code set: 1 Cause for concern 2 Getting help 3 No pressing concerns 4 Mostly OK 5 As good as it can be	Char (1)	Mandatory if Y reported at item 49
57	**Carer Star - Work**	cs_w	Matters related topaid work; support or welfare within paid work; desireto return to paid work	Code set: 1 Cause for concern 2 Getting help 3 No pressing concerns 4 Mostly OK 5 As good as it canbe	Char (1)	Mandatory if Y reported at item 49
58	**Blank**					
59	**Blank**					
60	**Blank**					
61	**Blank**					
62	**Blank**					
63	**Blank**					
64	**Blank**					
65	**Blank**					
66	**Blank**					
67	**Blank**					
68	**Blank**					
69	**Blank**					
70	**Blank**					

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Appendix 2 Family and Carers Monitoring Form 1: Registered Clients (2008 to 2018)

1. Service provider org: _____

2. Client ID: _____

3. Postcode of residence: _____

4. Local Health District (LHD)

- ☐ 1 Far West
- ☐ 2 Western
- ☐ 3 Sydney
- ☐ 4 SW Sydney
- ☐ 5 Southern
- ☐ 6 Murrumbidgee
- ☐ 7 Hunter NE
- ☐ 8 Northern NSW
- ☐ 9 Mid North Coast
- ☐ 10 Central coast 11
- ☐ Northern Syd 12
- ☐ Western Syd 13
- ☐ Nepean BM
- ☐ 14 Illawarra SH
- ☐ 15 SE Sydney

5. Date form was completed

day	*Month*	*Year*

6. Date of birth

day	*Month*	*Year*

7. Sex (tick one)

- ☐ 1 Female
- ☐ 2 Male
- ☐ 3 Unknown/ other

8. Main language spoken at home (tick one)

- ☐ 1 English
- ☐ 2 Other language, specify: _____

9. How did the client find out about yourservice (tick one)

- ☐ 1 Family/ friend
- ☐ 2 Brochure/ flyer
- ☐ 3 Advertisement
- ☐ 4 Acute mental health service/ hospitalSpecify unit/hospital if known:

  _____
- ☐ 5 Community mental health
  Specify unit if known:

  _____
- ☐ 6 Private psychiatrist
- ☐ 7 GP
- ☐ 8 Other government service
- ☐ 9 Other NGO
- ☐ **10** Other, specify:_____
- ☐ 11 Not known

10. Indigenous status

- ☐ 1 Aboriginal
- ☐ 2 Torres Strait Islander
- ☐ 3 Neither
- ☐ 4 Not known

11. Special needs group (tick one for each, donot leave any blank)

	Yes	No	Not known
a) CALD	☐	☐	☐
b) Physical or sensory impairment	☐	☐	☐
c) Geographical isolation	☐	☐	☐

12. How long in caring role (tick one)

- ☐ 1 Less than 6 mths
- ☐ 2 6 months–1 year
- ☐ 3 2–5 years
- ☐ 4 6–10 years
- ☐ 5 11–20 years
- ☐ 6 More than 20 yrs

13. Government pension/ benefit (tick all thatapply)

- ☐ 1 Carer allowance
- ☐ 2 Carer payment
- ☐ 3 Other pension/ benefit
- ☐ 4 No government pension/ benefit

14. Employment status (tick one)

- ☐ 1 Full-time
- ☐ 2 Part-time
- ☐ 3 Casual
- ☐ 4 Unemployed
- ☐ 5 Retired or not in labour force

15. Initial client needs (tick all that apply)

- ☐ 1 Information
- ☐ 2 Emotional support
- ☐ 3 Education and training
- ☐ 4 Advocacy
- ☐ 5 Referral

16. Number of people caring for: ☐

Details on up to two consumers that the client is caring for can be provided on this form.

Details on additional consumers can be provided on Form 1B

Consumer 1

17. Does the carer live with the consumer?

☐ 1 Yes ☐ 2 No

18. Carer relationship with consumer (carer isto the consumer .....) (tick one)

☐ 1 Parent
☐ 2 Partner
☐ 3 Sibling
☐ 4 Child
☐ 5 Grandparent
☐ 6 Friend/ neighbour
☐ 7 Ex family
☐ 8 Extended family

19. Consumer age group (tick one)

☐ 1 0–4 years
☐ 2 5–9 years
☐ 3 10–14 years
☐ 4 15–19 years
☐ 5 20–24 years
☐ 6 25–29 years
☐ 7 30–34 years
☐ 8 35–39 years
☐ 9 40–44 years
☐ 10 45–49 years
☐ 11 50–54 years
☐ 12 55–59 years
☐ 13 60–64 years
☐ 14 65–69 years
☐ 15 70–74 years
☐ 16 75+ years

20. Consumer sex (tick one)

☐ 1 Female ☐ 2 Male ☐ 3 Unknown/ other

21. Consumer mental illnesses (tick one primary and all secondary that apply)

Primary	Secondary	
☐ 1	☐ 1	Schizophrenia
☐ 2	☐ 2	Bipolar disorder
☐ 3	☐ 3	Schizo-affective
☐ 4	☐ 4	Personality disorder
☐ 5	☐ 5	Depression
☐ 6	☐ 6	Anxiety
☐ 7	☐ 7	Undiagnosed/unknown
☐ 8	☐ 8	Other, specify:_____

_____

22. Does the consumer also have..... (tick all that apply)

☐ 1 Intellectual disability
☐ 2 Acquired brain injury
☐ 3 Drug and alcohol abuse
☐ 4 Physical disability

23. Has the consumer had contact with LHD inlast 6 months?

☐ 1 Yes ☐ 2 No ☐ 3 Not known

24. Is the consumer's mental health managedby a primary care health professional or aprivate health professional?

☐ 1 Yes ☐ 2 No ☐ 3 Not known

Consumer 2

25. Does the carer live with the consumer?

☐ 1 Yes ☐ 2 No

26. Carer relationship with consumer (carer isto the consumer .....) (tick one)

☐ 1 Parent
☐ 2 Partner
☐ 3 Sibling
☐ 4 Child
☐ 5 Grandparent
☐ 6 Friend/ neighbour
☐ 7 Ex family
☐ 8 Extended family

27. Consumer age group (tick one)

☐ 1 0–4 years
☐ 2 5–9 years
☐ 3 10–14 years
☐ 4 15–19 years
☐ 5 20–24 years
☐ 6 25–29 years
☐ 7 30–34 years
☐ 8 35–39 years
☐ 9 40–44 years
☐ 10 45–49 years
☐ 11 50–54 years
☐ 12 55–59 years
☐ 13 60–64 years
☐ 14 65–69 years
☐ 15 70–74 years
☐ 16 75+ years

28. Consumer sex (tick one)

☐ 1 Female ☐ 2 Male ☐ 3 Unknown/ other

29. Consumer mental illnesses (tick one primaryand all secondary that apply)

Primary	Secondary	
☐ 1	☐ 1	Schizophrenia
☐ 2	☐ 2	Bipolar disorder
☐ 3	☐ 3	Schizo-affective
☐ 4	☐ 4	Personality disorder
☐ 5	☐ 5	Depression
☐ 6	☐ 6	Anxiety
☐ 7	☐ 7	Undiagnosed/ unknown
☐ 8	☐ 8	Other, specify:_____

_____

30. Does the consumer also have..... (tick all that apply)

☐ 1 Intellectual disability
☐ 2 Acquired brain injury
☐ 3 Drug and alcohol abuse
☐ 4 Physical disability

31. Has the consumer had contact with LHD inlast 6 months?

☐ 1 Yes ☐ 2 No ☐ 3 Not known

32. Is the consumer's mental health managedby a primary care health professional or aprivate health professional?

☐ 1 Yes ☐ 2 No ☐ 3 Not known

Appendix 3 FCMHP LHD reporting template

Program: Family and Carer Mental Health Program (F&CMHP)				
LHD:				
Reporting Period:				
Service Unit Entity code:	F&CMHP			
Supplementation Details (for full financial year)		amounts shown are for the full financial year		
Funding	$	-		
Reporting		ENTER DATA ONLY IN THE BLUE CELLS BELOW		
Staff FTE				
i. Total number of staff FTE employed under this supplementation	total FTE no.			
ii. Details of staff FTE employed under supplementation	FTE no., Clinical or Non-clinical and Staff Type	FTE No.	Clinical / Non-clinical	Staff Type
Activity				
iii. Training and Education (hrs)	actual hours of family and carer training and education including workshops, development of resources, inservices etc			
iv.Service development (hrs)	actual hours of service development activities including evaluations, surveys, research, quality improvement, policy, clinical governance etc			
v. Direct Carer Support (hrs)	Actual hours spent with a specific carer to provide assistance, advice and support (either face-to-face, telephone or by email). Please include the hours spent in providing non face-to-face support for these carers, such as consultation with the treating team, advocacy, referrals, travel, care planning and clinical note writing.			
vi. Indirect Carer Support (hrs)	Actual hours spent on other carer support related activities that is not otherwise recorded in eMR, including liaison and consultation with clinical and other staff, co-deisgn (carer partners supported to sit on Committees), partnership development and complaints or incident review management.			
Other				
vii. Any additional comments	additional qualitative and/or quantitative comments			

Instructions for completing template

i. Identify the total number of staff FTE employed under the F&CMHP supplementation as at period end e.g. 1.0.

ii. Provide details of staff FTE employed under this supplementation i.e. detail the total FTE reported at i. for each staff type and function e.g. *FTE no.:* 0.5; *Clinical/Non-clinical:* Clinical; *StaffType:* Clinical Nurse Consultant.

vii. Any additional comments - any other information that might be relevant including time spent travelling, time spent with targetted groups (CALD, ATSI, LGBTQI) etc.

Additional Notes

1. This report is for a SIX month period.
2. Data should only be entered in the blue cells, other cells are protected and cannot be changed.

Appendix 4 FCMHP Carer Experience Survey

FCMHP Carer Experience Survey

We are interested in learning about the experiences of people who are involved in the Family and Carer Mental Health Program. By completing this survey you will help us to further understand how to improve the health and wellbeing of families and carers and best support them in their caring role.

- The questions should take about 15 minutes to complete.
- You are able to skip any questions that you would prefer not to answer.
- There are some comment boxes included where you are invited to provide additional feedback.

All responses will remain anonymous.

The following questions are about Family and Carer Mental Health Program services

1. Which organisation do you receive services from
- ☐ CatholicCare Wilcannia-Forbes
- ☐ Mission Australia
- ☐ One Door
- ☐ Parramatta Mission
- ☐ Stride
- ☐ Justice Health and Forensic Mental Health Network

2. How long have you been involved in the Family and Carer Mental Health Program?
- ☐ Less than 6 months
- ☐ 6 months to <1 year
- ☐ 1 year to <2 years
- ☐ 2 years to <3 years
- ☐ 3 years or more

3. How did you find out about the Family and Carer Mental Health Program? (please select all that apply)
- ☐ Inpatient mental health service
- ☐ Other clinical mental health service
- ☐ Community Managed Support Service (including the provider of the FCMHP)
- ☐ General Practitioner
- ☐ Family or friend
- ☐ Website/social media
- ☐ Other: please specify (*optional*)_____

4. How often are you involved in any of the services and activities provided by the Family and Carer Mental Health Program?

- ☐ Every 1 to 2 weeks
- ☐ Once a month
- ☐ Once every 3 months
- ☐ Once every 6 months
- ☐ Once a year

5. Are you satisfied with how often you are involved in the Family and Carer Mental Health Program?

- ☐ Yes
- ☐ No

  If no, what prevents or makes it difficult for you to be involved in the Program as often as you would like? (please select all that apply)

  - ☐ The services or activities that are offered are not always useful or relevant to me
  - ☐ Language and/or cultural barriers make it difficult to participate
  - ☐ The travel required to get to the service location/s
  - ☐ The hours that services and activities are offered do not suit me
  - ☐ My caring role commitments
  - ☐ My paid employment commitments
  - ☐ Other commitments
  - ☐ Poor or no access to the internet to participate in online services and activities
  - ☐ Other: please specify (*optional*)

    _____

6. What activities have you been involved in with the Family and Carer Mental Health Program? (please select all that apply)

- ☐ One-to-one information and support (including referrals)
- ☐ One-to-one education and training
- ☐ Group information and support
- ☐ Group education and training
- ☐ Advocacy services
- ☐ Respite services
- ☐ Other: please describe (*optional*)

  _____

Please indicate your level of agreement with the following statements

7. My involvement in the Family and Carer Mental Health Program has had a positive impact on my health and well-being.

- ☐ Strongly agree
- ☐ Agree
- ☐ Neutral
- ☐ Disagree

- ☐ Strongly disagree

8. My involvement in the Family and Carer Mental Health Program has had a positive impact on the person I support.

- ☐ Strongly agree
- ☐ Agree
- ☐ Neutral
- ☐ Disagree
- ☐ Strongly disagree

9. Overall, I am satisfied with the services and supports offered by the Family and Carer Mental Health Program.

- ☐ Strongly agree
- ☐ Agree
- ☐ Neutral
- ☐ Disagree
- ☐ Strongly disagree

Questions 10-14 ask for your comments about the Family and Carer Mental Health Program

10. Are you planning to continue to be involved with the Family and Carer Mental Health Program?

- ☐ Yes
- ☐ No
- ☐ Not sure

Please comment on your answer (*optional)*

_____

_____

_____

11. Has the COVID-19 pandemic changed how you interact with or view the Program?

- ☐ Yes
- ☐ No

If yes, how (*optional)*

_____

_____

_____

12. What do you like most about the Family and Carer Mental Health Program?

_____

_____

_____

13. What could be improved about the Family and Carer Mental Health Program?

_____

_____

_____

14. If there is anything else you would like to share about your experience with the Family and Carer Mental Health Program, please comment.

_____

_____

_____

_____

The following are general questions about you. This information helps to get a better understanding of the needs of carers with different life experiences.

15. What is your relationship to the person you support?

- ☐ Spouse/partner (including married and defacto)
- ☐ Son or daughter (including step and in-law)
- ☐ Parent (including step and in-law)
- ☐ Brother or sister (including step and in-law)
- ☐ Friend
- ☐ Other

16. How long have you been supporting your family member, partner or friend with a mental illness?

- ☐ Less than 6 months
- ☐ 6 months to <1 year
- ☐ 1 year to <2 years
- ☐ 2 years to <5 years
- ☐ 5 years to <10 years
- ☐ 10 years or more

17. Does the person you support usually live with you?

- ☐ Yes
- ☐ No

  If No, please indicate what type of accommodation

- ☐ Supported accommodation
- ☐ Living with other family
- ☐ Living independently
- ☐ Other

18. What is the postcode where you reside _____

19. What is your gender?

- ☐ Male
- ☐ Female
- ☐ Other

20. What is your age group?

- ☐ <30
- ☐ 30-39
- ☐ 40-49
- ☐ 50-59
- ☐ 60-69
- ☐ ≥70

21. Country of birth

- ☐ Australia
- ☐ Other
  If Other, please specify _____

22. Are you of Aboriginal and/or Torres Strait Islander origin?

- ☐ Nether Aboriginal or Torres Strait Islander
- ☐ Yes - Aboriginal
- ☐ Yes - Torres Strait Islander
- ☐ Yes - Aboriginal and Torres Strait Islander

23. What is the main language you speak at home?

- ☐ English
- ☐ Other
  If Other, please specify _____

24. Did someone help you complete this survey?

- ☐ No
- ☐ Yes – a staff member from the Family and Carer Mental Health Program
- ☐ Yes – language or cultural interpreter
- ☐ Yes – family member, partner or friend
- ☐ Yes – someone else

Thank you for completing the survey and providing your valuable feedback.

Optional Interview: We would also like to invite a small number of survey participants to participate in an optional interview about your experiences with The Program. You do not have to do the interview if you do not want to.

If you would like to express an interest in participating in an interview please contact Pam by telephone on 02 4221 4411 or by email - pamg@uow.edu.au - by 31 July for further information.

Appendix 5 Stakeholder interview questions: LHDs

1. What is your role in the Family and Carer Mental Health Program (FCMHP) and how long have you been involved with the Program?

2. How well do you think that the FCMHP meets the mental health needs of families and carers?

3. Are FCMHP services more effective for some clients than others?

4. Has FCMHP created opportunities for families and carers to use a more appropriate range of services? For example, do clients now access a greater number of services?

5. Do you think the quality of care provided to families and carers has improved?

6. What major outcomes has the FCMHP achieved for families and carers, service providers, and the health care system?

7. Are providers of the FCMHP able to refer clients to external services that they need?

8. Are family and carer service providers able to access adequate staff training?

9. How easy has it been to establish and maintain effective relationships with FCMHP stakeholders?

10. Would you make any structural changes to the way that the FCMHP operates?

11. Have there been any COVID-19 impacts on the FCMHP?

12. Do you have any additional questions or comments?

Appendix 6 Stakeholder interview questions: CMOs

1. What is your role in the Family and Carer Mental Health Program (FCMHP) and how long have you been involved with the Program?

2. How well do you think that the FCMHP meets the mental health needs of families and carers?

3. Are FCMHP services more effective for some clients than others?

4. Has FCMHP created opportunities for families and carers to use a more appropriate range of services? For example, do clients now access a greater number of services?

5. Do you think the quality of care provided to families and carers has improved?

6. What major outcomes has the FCMHP achieved for families and carers, service providers, and the health care system?

7. Are providers of the FCMHP able to refer clients to external services that they need?

8. Are family and carer service providers able to access adequate staff training?

9. How easy has it been to establish and maintain effective relationships with FCMHP stakeholders?

10. Do you think the FCMHP improves the family inclusive aspect of your service?

11. Would you make any structural changes to the way that the FCMHP operates?

12. Have there been any COVID-19 impacts on the FCMHP?

13. Do you have any additional questions or comments?

Appendix 7 Stakeholder interview questions: Other FCMHP stakeholders

1. What is your role in the Family and Carer Mental Health Program (FCMHP) and how long have you been involved with the Program?

2. How well do you think that the FCMHP meets the mental health needs of families and carers?

3. Are FCMHP services more effective for some clients than others?

4. Has the FCMHP created opportunities for families and carers to use a more appropriate range of services? For example, do clients now access a greater number of services?

5. What major outcomes has the FCMHP achieved for families and carers, service providers, and the health care system?

6. Are providers of the FCMHP able to refer clients to external services that they need?

7. How easy has it been to establish and maintain effective relationships with FCMHP stakeholders?

8. Do you think the FCMHP improves the family inclusive aspect of services for family members and carers?

9. Would you make any structural changes to the way that the FCMHP operates?

10. Are you aware of COVID-19 having any impacts on the FCMHP?

11. Do you have any additional questions or comments?

Appendix 8 FCMHP Carer Experience Interview Discussion Guide

1) Please tell us about your overall experience with the Family and Carers program.
   a) How long have you been receiving support through this program?
   b) What do you like about the program?
   c) What don't you like about the program?

2) Please tell us about the support and activities you get from the Family and Carers program.
   a) What types of support do you receive?
   b) What activities do you participate in?
   c) How useful and relevant have the support you have received and the activities you have attended been to you?
   d) What could make support and activities offered more useful or relevant to you?

3) How accessible is the Family and Carers program to you?
   a) What helps you to access support and participate in activities?
   b) What could be improved to help you access support and participate in program activities?

4) How has your involvement in the Family and Carer Mental Health Program impacted on your health and wellbeing?

5) How has your involvement in the Family and Carer Mental Health Program impacted on the health and wellbeing of the person you support?

6) How has the COVID-19 pandemic changed how you interact with or view the Program?

7) Overall, how satisfied are you with the services and supports offered by the Family and Carer Mental Health Program. Why?

8) What could be improved about the Family and Carer Mental Health Program?

9) Is there anything else you would like to share about your experience with the Family and Carer Mental Health Program.