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

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

Abstract

The purpose of this report is to provide a summary of the Family and Carer Mental Health Program evaluation that 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. The study was completed between June 2020 and September 2021. Detailed information on all aspects of the evaluation were provided to the Ministry in two associated reports: an interim report submitted in March 2021 and a final report in December 2021.

The evaluation was conducted 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. It is the first evaluation of the FCMHP since it commenced operating in 2005.

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CHSD
centre for health service development

Evaluation of NSW Family and Carer Mental Health Program

Summary Report

January 2022

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australian health services research institute
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About the FCMHP evaluation reports

Three reports have been produced for the FCMHP evaluation:

- This 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.
- The final 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.
- 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

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We extend our deepest thanks to the families and carers who generously offered their time to share their experiences through participation in the carer survey and interviews. We would also like to particularly thank the five Community Managed Organisations (CMOs) and the JH&FMHN for their involvement in administering the carer survey, which was a key component of the study. CMO staff also participated in stakeholder interviews and other discussions, along with the LHDs and other key stakeholders, and we extend our thanks to everyone involved for their thoughtful and insightful contributions. Finally our thanks go to Mr Lam Huynh, Mr John McShane, and particularly Ms Francesca Frino from the NSW Ministry of Health for their ongoing support throughout the evaluation.

Executive summary

There is an abundance of evidence to support the crucial role of carers in providing support for people with mental health illness.[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 illness.

The evaluation was completed between June 2020 and December 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. Findings from Phase 2 are included in this summary final report and the more detailed final report submitted to the Ministry in January 2022.

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 was conducted with more than 200 carers providing feedback on their experiences of the

[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.

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

The purpose of this report is to provide a summary of the Family and Carer Mental Health Program evaluation that 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. The study was completed between June 2020 and September 2021. Detailed information on all aspects of the evaluation were provided to the Ministry in two associated reports: an interim report submitted in March 2021[3] and a final report in December 2021.[4]

The evaluation was conducted 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. It is the first evaluation of the FCMHP since it commenced operating in 2005.

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?

[3] 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.
[4] Gordon R, Grootemaat P, Loggie C, Rahman M, O'Shea P. (2021) Evaluation of NSW Family and Carer Mental Health Program: Final Report. Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong.

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 also occurred throughout the evaluation.

2 Overview 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. The program is delivered in partnership between specialist CMOs, LHDs and the 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. The first is 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.

The second FCMHP strategy is to improve the wellbeing of families and carers of mental health consumers through activities designed to achieve the core objectives.

2.1 Program origins and development

The FCMHP was officially launched by the NSW Minister for Health in 2005. It evolved from the Working with Families program, first established in 1996 at Sutherland Mental Health Service, as well as a number of subsequent programs which were funded to increase knowledge about how best to support carers and promote a family friendly culture in adult mental health services across NSW[5].

The theory underpinning the FCMHP originated from a paper published in 2005 by Mottaghipour and Bickerton[6]. The authors 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 the proven effectiveness in reducing patient relapse rate and family distress. They argued that with minimal extra training and a general framework, clinicians can incorporate family work in their everyday practice. They also described a Pyramid of Family Care, based on the conceptual work of Maslow's Hierarchy of Needs, that starts with the family's basic needs for connection and assessment, followed by general

[5] Detailed information about the background and context of the FCMHP is available in the interim evaluation report: 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, pp. 6-17.

[6] 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.

education, up to the top level of complex needs. In 2006, Mottaghipour et al also discussed a capacity-building framework comprised of three components: increasing workforce knowledge and skills; increasing organisational support; and developing/ensuring appropriate resources.[7]

The FCMHP has continued to develop over the years, building on strategic documents and directed by both State and Commonwealth policy and legislative frameworks. Increasingly, these have acknowledged and formalised the role of families and carers in the recovery of consumers and the delivery of mental health services more broadly.

At a state level, the strategy underpinning the FCMHP includes a major ten-year reform agenda with a core focus of building an effective and integrated community support sector. Recently, the NSW Mental Health Commission released *Living Well in Focus 2020-2024*[8], a mid-term review and update of the reform plan. 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.

2.2 Funding, structure and governance

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.

The program framework was most recently reviewed and updated in 2017 through a workshop process. Details are available at the NSW Health website.[9] Under the current FCMHP arrangements, five CMOs deliver services across NSW with one working in partnership with each of the LHDs, as shown in Table 1.

Table 1 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[10]	Central Coast, Nepean Blue Mountains, Northern Sydney Western Sydney
Stride	Illawarra Shoalhaven, South East Sydney

[7] 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.
[8] Mental Health Commission of NSW (2020) *Living Well in Focus: 2020-2024*.
[9] NSW Health (2018) NSW Family and Carer Mental Health Program framework (available www.health.nsw.gov.au/mentalhealth/services/carers/Pages/support-framework.aspx).
[10] 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.

Funding and Performance Agreements for the CMOs are centrally managed by the Ministry. The CMOs and LHDs negotiate Service Level Agreements (SLAs) for the management and co-ordination of the program, and 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 Ministry also convenes a FCMHP statewide steering committee, comprising members from all the LHDs and CMOs, as well as the JH&FMHN and carer and other key stakeholder representatives.

The FCMHP Minimum Data Set (MDS) is used to provide consistent monitoring of CMO program activities. A new version was implemented in 2018 which incorporated the Carers Star tool[11] for implementation by the CMOs as a carer assessment tool. MDS data 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 there are four key data items to be reported six-monthly.

2.3 Delivery of the program

The program is fundamentally a partnership approach between the LHDs and CMOs, with each generally undertaking different aspects of the FCMHP, although there is some degree of overlap:

- CMOs provide specialist services to carers by a team that generally includes a Program Coordinator and support workers. They provide community based education and training, individual support and advocacy services, and a range of group activities including support groups.
- LHDs generally employ a Program Coordinator as a minimum for the program. In addition to organising referrals to the CMO, LHD services can include face-to-face services to carers, 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 JH&FMHN is also part of the FCMHP with a Program Coordinator located at Long Bay Hospital within the Long Bay Correctional Complex. The program at JH&FMHN includes families and carers from across NSW and as such interacts with all CMOs. This arrangement is formalised in a Memorandum of Understanding (MOU).

[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/).

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.[12] 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.[13]

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[14]) 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.

[12] 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.
[13] 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.
[14] 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[15] 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 the current FCMHP MDS are presented in Section 5.1 and 5.2.

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 5.3.

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

[15] 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 associated with the COVID 19 pandemic. The results of the analysis of the LHD dataset are presented in Section 5.4.

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 5.5.

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.[16]

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. The discussion guide for the carer interviews is shown at Appendix 8.

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

[16] 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).

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 a model was developed as an output of the evaluation. Program logic development is an iterative process, and a period of consultation was undertaken with relevant stakeholders during the evaluation. The draft model was presented at the FCMHP Statewide Network meeting which was followed by further communications with members. Feedback was used to inform the development process through to the final version, which is presented in Figure 1.

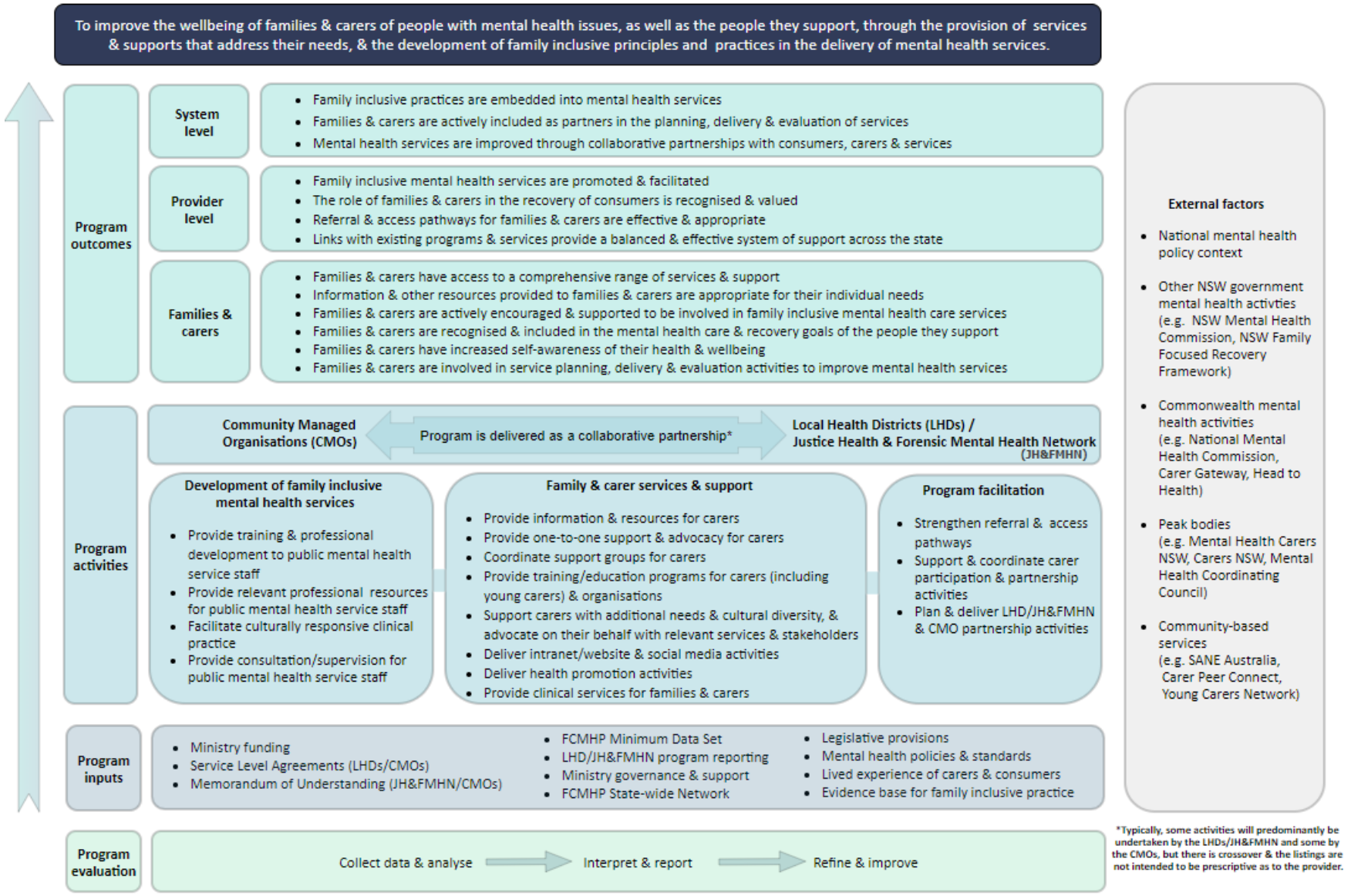
The particular design of the model was selected as it is well suited to the retrospective development of a program logic for a mature program. The logic flows from the 'foundation' level at the bottom, up to the overarching 'purpose' level at the top, representing the way in which each of the elements 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 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 1 Family and Carers Mental Health Program - Program Logic



5 Results: Quantitative data

An important objective of the analyses 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.

5.1 The FCMHP Minimum Data Set

An outline of the FCMHP MDS was provided in Section 3.1.1. The evaluation received 16,540 data items/observations for 6,201 distinct carers who were supported by the five CMOs across different LHDs between July 2018 and September 2020.

5.1.1 Demographic characteristics

Table 2 shows the demographic and referral source characteristics of carers who received support. Of note, the most common age group of carers was 50-59 across all CMOs except Catholic Care (40-49), and almost 80% of carers across all CMOs were female with a similar number born in Australia. While around 15% of carers did not speak English at home, very few required an interpreter. 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%. The predominant referral source was a public mental health service, followed by self-referral.

Table 2 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) (%)
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	31.6	22	24.6	22.8
70-80	12.2	15	18.1	12.5	12.4	13.1
≥80	3	5.1	3.8	2.6	2.1	2.9
Sex						
Male	18.4	20	18.7	21.1	24.7	21.1
Female	81.6	80	81.3	78.7	75.2	78.8
Country of birth						
Australia	80.8	96	82.1	76.5	72.2	78.3
Outside Australia	19.2	4	17.9	23.5	27.8	21.7

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) (%)
Indigenous status						
Indigenous	4.2	14	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	99.8	97.5	100	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	15.5	39.1
Public Health Service	2.6	10.7	5.9	1.5	4.6	3.3
General practitioner	0.4	0	0.2	0.1	0.2	0.2
Other Private Health	3	0	2.1	0.8	0.4	1.1
Service						
CMO (Different Provider)	4	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	1.3	5.3	5.7	1.9	3.7
Unknown/not stated	0	1.1	1.1	6.5	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	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	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

5.1.2 Level of support provided

The FCMHP MDS captures detailed activity data in three broad categories: individual support, group support, and indirect support. The times reported for the activities reported against each category, is presented below, broken down by metropolitan and regional LHDs.

Individual support

A summary of minutes of individual support is shown in Table 3. 'Information' was the most frequently reported support in terms of the number of clients, followed closely by 'emotional' support, which had the largest number of reported minutes. Carers in

metropolitan LHDs received statistically significantly more minutes of support than carers in regional LHDs in the these two most frequently used services. This contributed to a statistically significantly greater number of total minutes of support being received by carers in metropolitan LHDs than regional LHDs (195 minutes vs 168 minutes; p<0.001).

Table 3 Individual support: metropolitan vs regional (Jul 2018 to Sep 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).

Group support

A summary of minutes of group support is shown in Table 4. The highest number of carers received 'Education and training' support, which also had the largest number of reported minutes. Overall, a noticeably higher proportion of carers in metropolitan LHDs received at least one type of group support (47% vs 36%). However, this difference in overall levels of group support services received was not statistically significant, with the median length of support time being 405 minutes compared with 360 minutes.

Table 4 Group support minutes: metropolitan vs regional LHDs (Jul 2018 to Sep 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).

Indirect support

A summary of minutes of group support is shown in Table 5. Over three quarters of carers received 'program admin' service, with similar carer numbers reported in each of the LHD areas, however there was a statistically significant higher median time reported in metropolitan versus regional LHDs (75 minutes vs 60 minutes). A substantially higher proportion of carers received indirect travel support (travel to and from carer) in metropolitan compared with regional LHD, and similarly there was a significant difference in the number of minutes provided (90 vs 60).

Table 5 Indirect support minutes: metropolitan vs regional LHDs (Jul 2018 to Sep 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).

5.1.3 Predictors of support

The levels of individual, group and indirect support services reported above were further analysed to examine associations between sociodemographic characteristics and levels of support services received. For this analysis, multivariate linear regression was used to predict the amount of support received by carers between July 2018 and September 2020. Because of the skewed distribution of levels support received, the regression model was performed after log-transformation. Table 6 shows the regression results in percentages and 95% confidence intervals (CI).

Being a younger carer (age <40) compared with carers aged 40-64 was statistically significantly associated with receiving less support in all categories (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 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.

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 across all categories.

Table 6 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

5.2 Carers Star outcome

The Carers Star 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 tool are provided in Appendix 1.

5.2.1 Carers Star Outcomes by carers' characteristics

Table 7 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. The proportion of carers reporting better outcomes varied across the six different domains. The majority of carers reported better outcome in 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'. Of note was the higher proportion of older carers (age ≥65) who reported better outcomes across all domains of the Carers Star (except for Health) than other age groups.

Table 7 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%
Sex							
Male	892 (20)	62%	44%	62%	55%	43%	67%
Female	3,474 (80)	52%	41%	58%	45%	37%	66%

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
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 carers (29%, n = 1,830) who did not complete Carers Star.

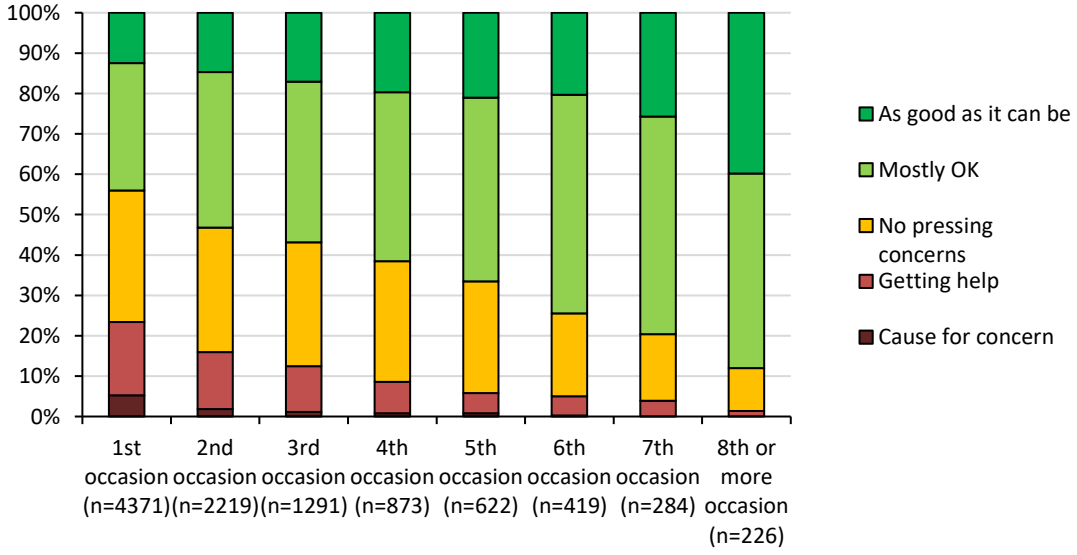
5.2.2 Longitudinal analysis of Carers Star outcomes

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, showing changes in scores across eight (or more) time points between July 2018 and October 2020.

5.2.2.1 Carers Star: 'Health' domain

Figure 2 shows changes in scores for the Carers Star 'Health' domain, with a clear trend being 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.

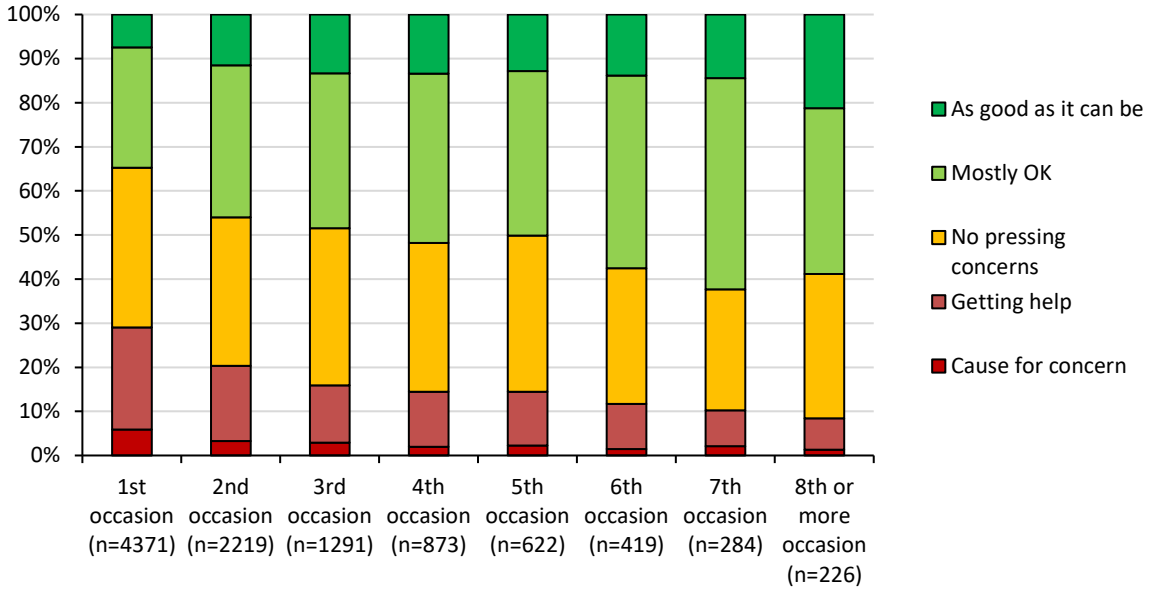
Figure 2 Changes in Carers Star 'Health' domain (Jul 2018 to Sep 2020)



5.2.2.2 Carers Star: 'The caring role' domain

Figure 3 shows changes in scores for the Carers Star 'The caring role' domain, with again, 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.

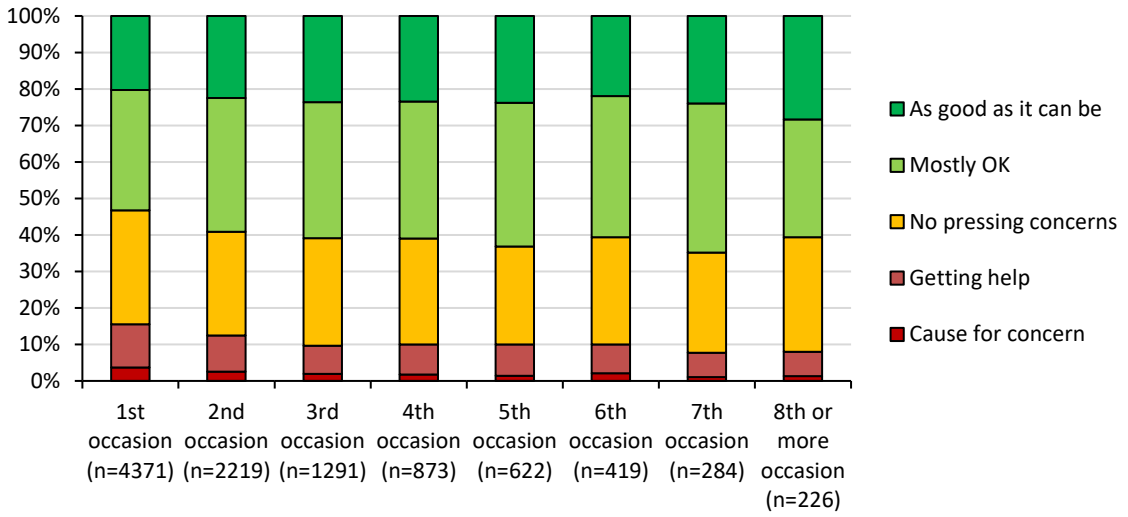
Figure 3 Changes in Carers Star 'The caring role' domain (Jul 2018 to Sep 2020)



5.2.2.3 Carers Star: 'Managing at home' domain

Figure 4 shows changes in scores for the Carers Star 'Managing at home' domain. 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.

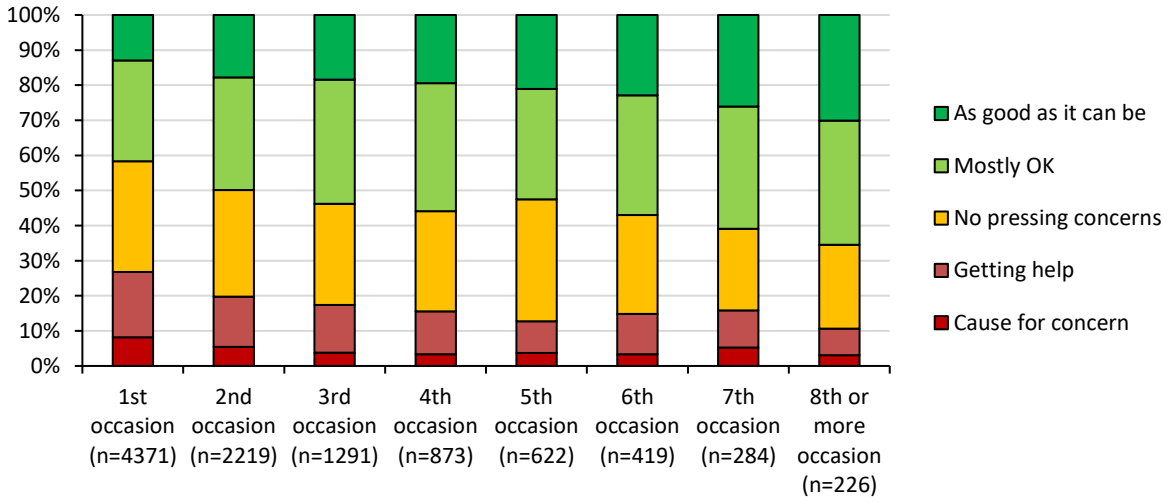
Figure 4 Changes in Carers Star 'Managing at home' domain (Jul 2018 to Sep 2020)



5.2.2.4 Carers Star: 'Time for yourself' domain

Figure 5 shows changes in scores for the Carers Star 'Time for yourself' domain. 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 5 Changes in Carers Star 'Time for yourself' domain (Jul 2018 to Sep 2020)

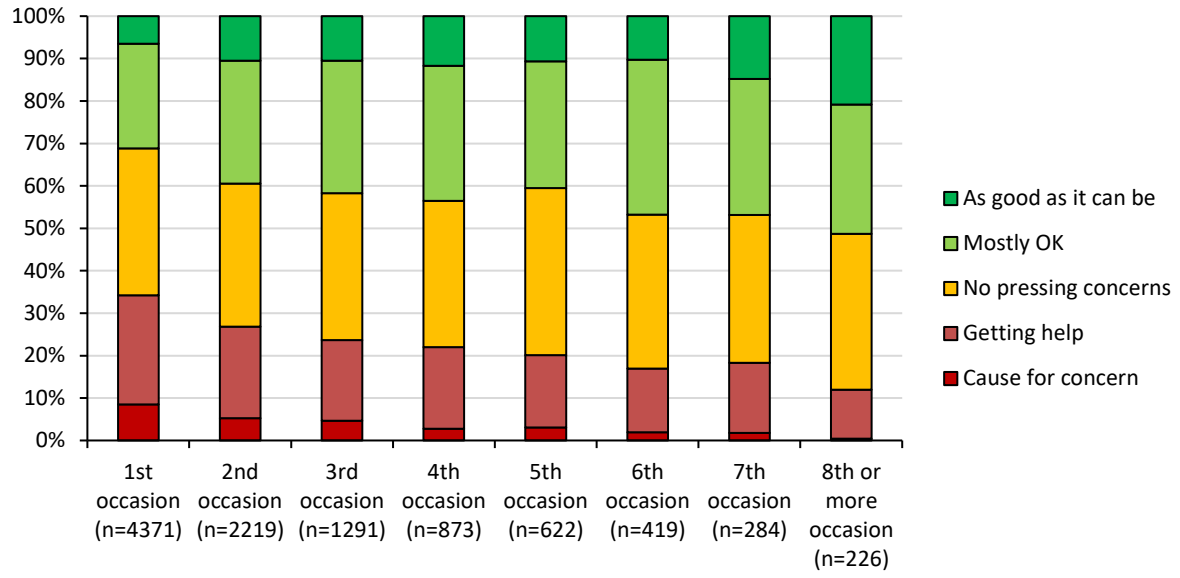


5.2.2.5 Carers Star: 'How you feel' domain

Figure 6 shows changes in scores for the Carers Star 'How you feel' domain. 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.

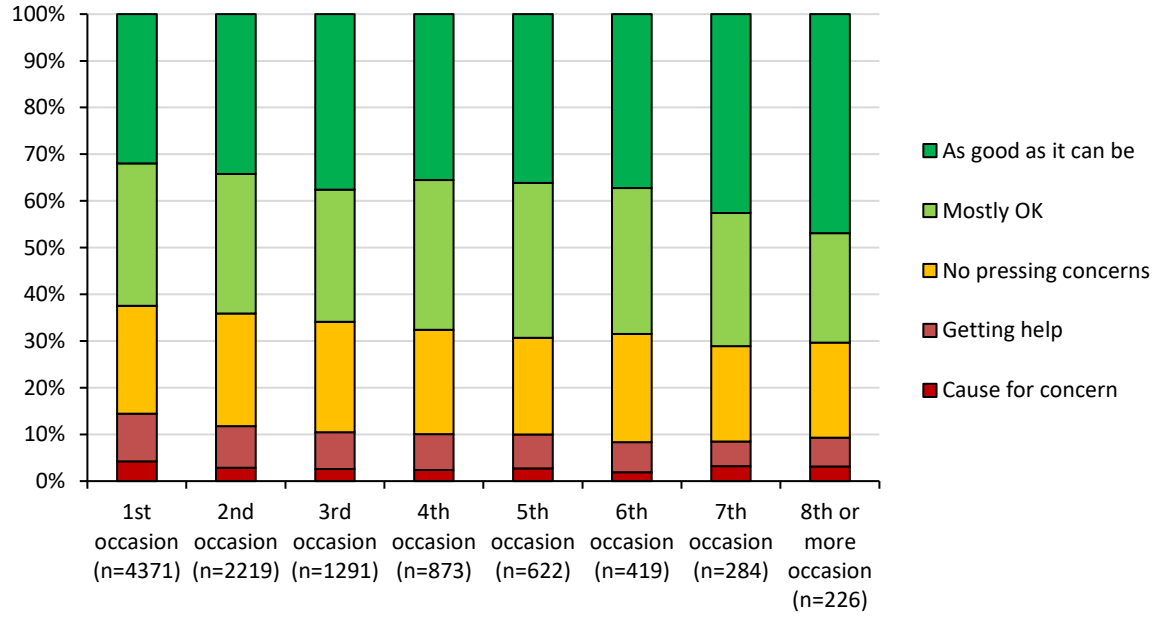
Figure 6 Changes in Carers Star 'How you feel' domain (Jul 2018 to Sep 2020)



5.2.2.6 Carers Star: 'Finance' domain

Figure 7 shows changes in scores for the Carers Star 'finance' domain. 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 7 Changes in Carers Star 'Finance' domain (Jul 2018 to Sep 2020)



5.3 Historical FCMHP data

5.3.1 Registered client and consumer data

Over the different reporting periods from October 2008 to June 2018, a total of 16,506 carers were registered by seven CMOs providing program services, receiving a total of 330,513 records of contacts and services. 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 a 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 action/results[17], 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 consumer data consisted of 18,423 consumers who had been cared for/supported by 15,990 carers. The majority of consumers were cared for by parents (53%), followed by partner (19%), child (11%) and sibling (7%). Almost, two-thirds of consumers lived with their carers (65%).

5.3.2 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 8). 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 8). 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 8 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: Differences between mean score at initial assessment and at follow-up were significant at $p<0.001$.

5.3.3 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%,

[17] The action/results were not mutually exclusive as a record of service and contact can include multiple actions/results.

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.

5.4 LHD FCMHP dataset

5.4.1 Summary of LHD data

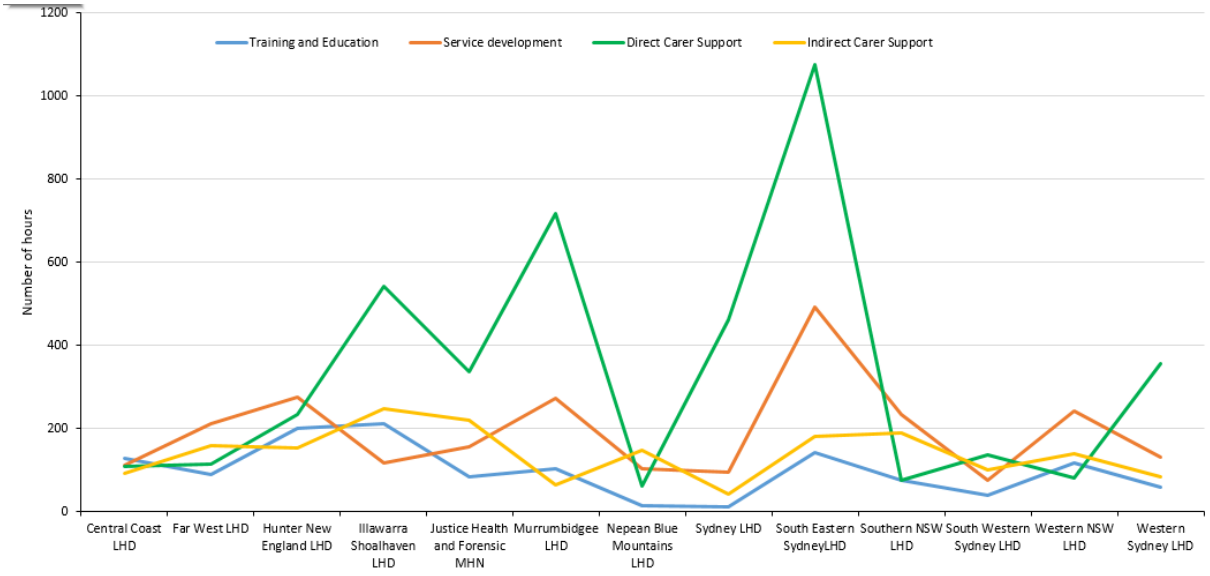
There were deficiencies observed in the reporting which need to be considered in analysis and interpretation of the data. From an expected total of 48 reports, there were 42 reports provided (14 for Jul-Dec 2019, 15 for Jan-Jun 2020, 13 for Jul-Dec 2020). Data quality issues were observed, including:

- FTE and activity hours sometimes include a combination of FCMHP and other program data (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 periods are inconsistently included in the total FTE;
- FTE data was reported without any activity hours;
- Program data reported in the 'additional comments' text box are not consistently also included in the data totals.

The total number of program activity hours by the average FTE reported for each LHD were compared for 13 LHDs (3 were excluded due to low activity hours) which showed considerable variation between the LHDs. However, any use of this data to assess productivity and compare across LHDs should be treated with caution.

Figure 8 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. Training and education has the least number of hours in more than half the LHDs and the lowest total overall. Again, these results should be considered unreliable.

Figure 8 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 of its application.

5.5 FCMHP Carer Experience Survey

The Carer Experience Survey (refer Appendix 4) was completed during August 2021 and September 2021 by 203 clients of FCMHP CMOs and JH&FMHN. The responses to the closed questions in the survey were categorised into four groups for analysis, as follows:

- Participant characteristics: including demographic details and information about their caring role;
- Service-related characteristics: including details about their engagement with the CMOs;
- Impact of the services and support offered by the FCMHP: including impacts and overall satisfaction with the program;
- Carers' involvement in the FCMHP: the program activities in which carers participated.

The results of an analysis of the length of time survey participants were involved in the FCMPH relative to the length of time in a supporting role are also presented below.

5.5.1 Carer Experience Survey – Participant characteristics

The profile of the survey participants was compared with the 6,201 clients 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%).

Survey specific data showed that 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%). 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. A detailed description of the participant characteristics is provided at Appendix 9.

5.5.2 Carer Experience Survey - Service-related characteristics

Table 9 shows the service-based 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. 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.

Table 9 Carer Experience Survey - Service-related characteristics

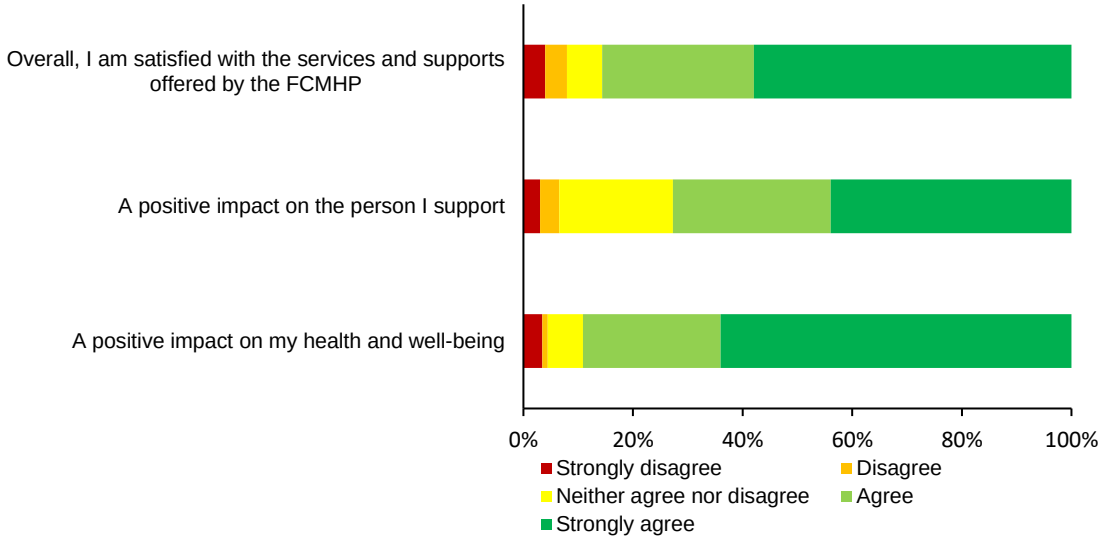
Service-based Characteristics	Carer Survey (n=204) Jul-Aug 2021		% in the FCMHP-Jul 2018-Sep 2020 (N=6201)
	n	%	
Community Managed Organisation (CMO)			
Catholic Care Wilcannia-Forbes	17	8.3	7.7
Mission Australia	37	18.1	7.7
One Door Mental Health	65	31.9	50.4
Uniting	38	18.8	18.3
Stride	33	16.2	16.0
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	-
3 years or more	79	38.7	-
How often involved in FCMHP			
Every 1 to 2 weeks	38	19.2	-

Service-based Characteristics	Carer Survey (n=204) Jul-Aug 2021		% in the FCMHP-Jul 2018-Sep 2020 (N=6201)
	n	%	
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	-

5.5.3 Impact of the services and support offered by the FCMHP

Figure 9 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 9 Levels of agreement between impact and satisfaction with FCMHP (n=203)



5.5.4 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)', and around the same (48%) reported that they were involved in 'Group information and support'. Around one-third of survey participants participated in 'Group education and training', with smaller numbers participating in the remainder of the activity categories ('Advocacy services', 'Respite services', 'One-to-one education and training' and 'Other'; ranging from 11% to 16 %)

Table 10 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.

Table 10 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.[18] 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.

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. 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. The breakdown of interviews across the two phases of the evaluation is shown in Appendix 10.

In addition, 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 Appendix 11.

Finally, 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?

[18] 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).

- 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.

6.1 Results: Program structure, staffing and resources

6.1.1 Structure and governance

The overarching FCMHP structural and governance arrangements, where funding and performance agreements are managed centrally by the Ministry, were widely supported by program stakeholders. Within this structure, CMOs and LHDs negotiate SLAs to ensure an understanding of, and agreement to, respective roles and responsibilities.

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. From a structural perspective, some common elements were identified as being crucial to the success of the CMO model, including:

- CMO structures promoting strong partnerships with LHDs
- the CMO Program Coordinator role
- the availability of a suitable contact person to advocate for carers.

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 allow for a more strategic approach to reaching more carers across all of NSW, including groups such as CALD and Aboriginal and Torres Strait Islander people, and carers in regional 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. Increased communication between LHDs was identified as an important opportunity for the program.

KPIs and data collection

Participants were broadly happy with the current CMO KPIs with the targets felt to be realistic. 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.

There were some mixed views in relation to data collection. Some felt that data collection focussed too much on hard data rather than carer experiences and what they have achieved. Some participants felt that the Carers Star tool could sometimes be seen as a tick box exercise for collecting statistics, and that there may be a lack of consistency as to how the tool was applied. However, there were also positive views expressed about the tool with some staff commenting that it brought a positive change to how carers were assessed, and carers finding that it assisted the service working with them to set goals and give them purpose.

> *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)*

CMO and LHD participants spoke about having their own data collections as well as the FCMHP MDS to inform their practice. 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.

6.1.2 Staffing

There is variation in staffing structures across the FCMHP which 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. Conversely, there were those whose experience was of a fairly stable workforce.

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. 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. 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)*

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)*

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.

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.

> *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 most 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 multi-disciplinary positions 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. Being unable to offer counselling to families and carers creates challenges for support staff, with participants noting 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.

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

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

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 within 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.

> *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)*

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 support worker position, and others reported they had recruited Aboriginal 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.

There was a suggestion for strategies to be implemented 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 generally 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. LHDs provide training opportunities for their CMO partners, with invitations to staff in-services and FCMHP events.

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.

6.1.3 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.

> *…we all could use 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).*

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.

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. 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, including training and education material, pamphlets and booklets, and information packs.

Concerns raised around the lack of standard resources include:

- 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.

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. Badging program-specific resources as FCMHP would assist in raising the profile of the program with families and carers, clinicians and other stakeholders.

6.2 Results: Program effectiveness

6.2.1 Meeting carers' needs

In general, the FCMHPH is seen to meet the needs of the carers who access it. Participants generally agreed that the quality of care specific for carers has improved with the program, with support also more consistently offered with carers' needs identified through routine intake procedures and support plans.

Feedback from carers has indicated high levels of satisfaction with the program, including that program staff are good at engaging carers and understanding and working with their complex needs. Prior to engaging with the FCMHP, many carers have never been offered support previously, or been given an opportunity (and given themselves permission) to focus on their own needs. 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.

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

> *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)*

Most carers found that the program structure provided the range of support they needed, and appreciated that 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.

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, which was often an informal chat over coffee or a phone call. This provided a supportive ear and help to workshop some strategies, and 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 'mostly as a safety net' (carer interview).

> *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... I feel like, yep, I can do this, I feel more in control. (carer interview)*

Most carers really liked group forums and events which gave them an opportunity to connect with other people who understood and didn't judge. 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. Carers also saw the group activities and events as a form of 'time-out'.

> *I just look at it all as escapism from my horrible life. … Yes, it's good for me, for escape. (carer interview)*

Conversely, while most carers found sharing life experiences helpful and validating, some carers found talking about their own story and hearing the stories of others emotionally draining. For others the purpose or activity of the group had to be specifically meaningful to them.

Carers spoke about the value of education sessions that were offered, which included a range of topics related to mental health conditions and treatments, navigating mental health systems. These included sessions about helping carers to care for themselves, strategies to manage difficult situations, information about mental health conditions and treatment, and navigating mental health and other relevant systems. Program staff discussed 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. Education on carers' rights to participate in the care of their loved one is also offered, as well as the provision of strategies and direct support to carers to facilitate participation.

Another element of program success for carers 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. (carer interview)*

Some carer participants expressed a view that the support offered was infrequent, untimely or inadequate for their needs. A small number of carers cited examples of not feeling properly supported, with a few saying that their involvement in the program had been harmful to their mental health and wellbeing. Mandatory training for staff in Recovery Orientation, and Trauma Informed Practice was suggested to ensure that the program does not inadvertently cause harm.

6.2.1 Outcomes for carers

The program has improved the lives and wellbeing of carers, and helped them to better understand mental illness and how to care for their loved one as well as themselves. It has provided peer connections and support, and the 'permission', tools and space for self-care. It has also given carers the confidence to navigate health and support systems and to advocate for themselves and their loved ones.

In particular, carers felt that the program has helped them to focus more on themselves, leading to improvement in their health and well-being through focused education and information awareness sessions, support groups, peer connections and other initiatives. Most carers felt that their own perceptions of their importance and self-worth had increased as a result of their participation in the program. Program staff also reflected on the changes observed in carers as they access the support they needed.

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

Most carers reported that the program has had a positive impact on their family, with some reporting improved relationships within families. Carers reported that the program has helped to make them feel more hopeful and able to face the future.

> *My [support worker] is just amazing and kind and puts everything into perspective and makes me believe that I can do this. (carer survey)*

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

> *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)*

6.2.2 The carer profile in mental health services

An important finding was that the program has contributed to changes in practice and culture within mental health services by giving carers a voice, with CMO and LHD participants reporting that carers are now 'at the table' rather than 'on the periphery'. The inclusion of family and carers has been embedded in some services through building participation processes into practice. This increased participation of carers, at individual and process levels, has resulted in a significant 'shift' to valuing the lived experience of carers, with increasing recruitment of peer carer workers, the remuneration of carers in advisory and other roles, and clinicians now seeing carers as a resource they can draw on.

> *… 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)*

However, while there is evidence of practice and culture change, 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.

Participants reported that 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 noted that whilst there are tensions between the rights of carers and consumers, both have a legal and a moral right to participate, and family and carers often have a caring role whether the consumer recognises them as carers or not. Some participants discussed the importance of the continuing work in this aspect of the program.

Executive support was seen as an important element of success. Participants reported that in areas where the executive really understood, believed or 'championed' carer participation, it

was much more embedded in service delivery. Executive support also facilitated carer inclusion in governance and accountability processes, such as KPIs.

6.2.3 Carer participation in program and services design

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, including where carer peer workers are employed 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)*

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, as well as the FCMHP. Feedback from the carer survey and interviews showed little evidence of carers being involved in the governance of the program services at the local level, with some carers reporting a lack of known feedback mechanisms and that carers did not always get a positive response to feedback and complaints.

6.2.2 Access to the FCMHP services

Geographical barriers

There were issues raised around equity of access to the program in regional and remote areas, due to services not being available in all areas within LHDs. Some services are increasing access through video teleconferencing platforms, including telehealth, however this is not seen as being as effective at engaging or supporting carers as face-to-face services, and is unavailable or unacceptable for some carers. One carer also commented that program staff to client ratios are 'huge' in rural areas.

> *…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)*

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. Issues with a loss of program service related to changes in cross-border arrangements with Victoria were also raised.

Marginalised and/or minority groups

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. Participant suggestions to increase access to the program for this carer cohort included:

- recruiting Aboriginal and Torres Strait Islander peers to the program;

- providing extra resources to build partnerships the cultural capacity of program staff and other stakeholders (one LHD reported and improvement in Aboriginal carers' engagement following the employment of an Aboriginal staff member);
- involve more of the carer's extended family in the program.

CALD carers were largely happy with the program, although there appears to be a diversity of appropriate support for CALD groups depending on region. Some participants reported that full access to the program services may not be available to all CALD carers, especially when cultural issues and language remain as barriers. 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;
- separate bilingual support groups;
- inclusion of extended family.

While there are a number of initiatives underway to increase engagement of young carers and male carers, they are largely underrepresented in the program. Suggested strategies include:

- employment of male carer peer workers;
- building relationships with organisations that work with these groups (such as youth centres);
- tailoring services and supports to be specific to these cohorts.

Inconsistencies in service provision

Participants reported some issues with variations in the specific program services provided across the different CMOs and LHDs. An example was one-to-one support, with some providers doing regular check-ins with carers, but at least one service leaving 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. Some carers reported that inconsistencies in staffing structures and staff turnover are affecting the number of front line staff, with the potential to impact on face-to-face supports.

Flexibility on entry and exit to the program was seen as an element of success, although this varies between services. Some services have no time limit on access to programs, allowing 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, whereas some program services are time-limited. Some carers in services with end dates expressed anxiety about how they might cope once they could no longer access the service. However, the need to manage demand to enable new carers to enrol in the program was highlighted.

Strategies used to address this included what one participant called 'soft leaving methods', for example a cessation of one-to-ones support but continued engagement in social and information sharing/education events.

Some carers said that the programs do not offer enough options or flexibility in how the program is delivered, including that the time the services were 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, for example, in the home or closer to home. This was particularly important to carers in rural and remote areas.

Program awareness

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. Suggestions for more comprehensive promotion included information brochures being given to each and every family when their loved one enters the hospital or forensic systems, and information also being available in relevant services such as doctors' surgeries, chemists, police stations and any other places where carers may go for help.

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

> *…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 participants also raised concerns about the need for strategies to engage what some called 'hidden carers', such as people with a caring role who do not see themselves as 'carers', or carers who would feel guilty about attending the program. One CMO reported they had done a lot of work on identifying and engaging 'hidden carers' with the program.

6.2.3 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. 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, have prolonged the difficult circumstances and uncertainty that families and carers are experiencing.

> *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)*

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

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, leaving them at home 'potentially in psychologically or emotionally, physically unsafe environments' (CMO) and without a 'safe space' to talk openly about their issues.

> *…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)*

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, and there can also be a fear around presenting to health services such as hospital emergency departments because of the risk of contracting COVID.

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. 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)*

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. 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)*

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 continue to meet the needs of families and carers and successfully achieve the program objectives.

> *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.[19,20] NSW legislation explicitly recognises the important contribution that carers make and their need for support to continue in this role.[21] 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.[22]

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 funding streams. This is supported by a range of community-managed organisations and

[19] 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.
[20] 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.
[21] New South Wales Parliament (2010) NSW Carers (Recognition) Act 2010 No 20.
[22] Patton MQ (2002) *Qualitative Research & Evaluation Methods, 3rd Edition*. SAGE Publications, Thousand Oaks, California.

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[23]. 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.

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

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

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.[24] 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.

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.

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

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 that order.	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	'XXXXXDDMMYYYYN' Char (14)	Y

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Itemno.	Data item	Field header	Metadata definition	Cell content	Field size	Mandatory
			NOTE: SLK should beused in Carer Star.	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 component of the person's Date of	Code set: 1 Estimated 2 Not Estimated	Char (1)	Y

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Itemno.	Data item	Field header	Metadata definition	Cell content	Field size	Mandatory
			Birthwas 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 other administrative	Example: 2640	Char (4)	Y

Itemno.	Data item	Field header	Metadata definition	Cell content	Field size	Mandatory
			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 individual carer support in**	eduind_mins	Individual support: Educate or facilitate carers to	Example: 0120 is equivalent to 120 minutes	'NNNN' Char (4)	Y

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Itemno.	Data item	Field header	Metadata definition	Cell content	Field size	Mandatory
	4.Education andTraining		build knowledge and skills.			
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 travel to andfrom Carer**	travelst_mins	Travel - Time used totravel to and from carer to provide support.	Example: 0030 is equivalent to 30 minutes	NNNN' Char (4)	y

Itemno.	Data item	Field header	Metadata definition	Cell content	Field size	Mandatory
	13.Travel					
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 be	Char (1)	Mandatory if Y reported at item 49

Itemno.	Data item	Field header	Metadata definition	Cell content	Field size	Mandatory
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.

Appendix 9 Carer Experience Survey - Person-based characteristics

Person-based Characteristics	Carer Survey (n=203) Jul-Aug 2021		% in the FCMHP-Jul 2018-Sep 2020 (N=6,201)
	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%)

Appendix 10 Stakeholder interviews: participant profile

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

Appendix 11 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		