Evaluation of the NSW Family and Carer Mental Health Program: Interim Report

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Abstract
This is the interim report of the Family and Carer Mental Health Program (FCMHP) evaluation prepared by the Centre for Health Service Development at the Australian Health Services Research Institute (University of Wollongong). The Centre for Health Service Development has been commissioned to undertake this evaluation by the NSW Ministry of Health (the Ministry) between June 2020 and September 2021.

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Evaluation of the NSW Family and Carer Mental Health Program

Interim Report

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Evaluation of the NSW Family and Carer Mental Health Program: Interim Report – February 2021
Abbreviations used in this report

CALD  Culturally and Linguistically Diverse
CMO   Community Managed Organisation
FCMHP  Family and Carer Mental Health Program
InforMH  NSW Health Information for Mental Health
IQR   Inter quartile range
JH&FMHN  Justice Health & Forensic Mental Health Network
KPI   Key Performance Indicators
LHD   Local Health District
MDS   Minimum Data Set
NGO   Non-Government Organisation
the Ministry  The NSW Ministry of Health
TMHC  Transcultural Mental Health Centre
Executive summary

This is the interim report of the Family and Carer Mental Health Program (FCMHP) evaluation prepared by the Centre for Health Service Development at the Australian Health Services Research Institute (University of Wollongong). The Centre for Health Service Development has been commissioned to undertake this evaluation by the NSW Ministry of Health (the Ministry) between June 2020 and September 2021.

The key tasks for the FCMHP evaluation are to:

- 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 mental health services.

The evaluation includes both formative and summative components. The formative evaluation is investigating established processes and the extent to which existing networks, relationships and governance arrangements have influenced the program’s implementation. The summative evaluation will focus on the outcomes achieved by the FCMHP and the translation of those outcomes into future policy directions.

Data from various sources has been collected and analysed in the evaluation to date. This includes both quantitative data, primarily from the FCMHP Minimum Data Set (MDS), and qualitative data from interviews with key stakeholders. The purpose of this interim report is to present a set of formative evaluation findings based on the evaluation activities undertaken to date.

The scope of this report is to:

- Outline the structural arrangement of the program and the processes associated with the delivery of services;
- Present a draft FCMHP program logic for consideration by stakeholders;
- Present an analysis of current FCMHP MDS data collected routinely since October 2018 and earlier datasets;
- Present results of a thematic analysis of interviews with Community Managed Organisations (CMOs), Local Health District (LHD) staff and other key stakeholders; and
- Outline the approach to activities that will occur during the remainder of the evaluation.

Key findings to date

A range of findings have emerged in the FCMHP evaluation to date. One key outcome has been the development of a draft FCMHP program logic (refer Section 4). The program logic
aims to provide a clear summary of the objectives of the program and the interaction between its different elements. It is hoped that the final program logic will serve as an important tool for the management of the FCMHP in the future.

The results of a detailed analysis of the current FCMHP MDS data (between July 2018 and September 2020) are presented in Section 5. These data represent a valuable source of information not only for the evaluation itself, but for the FCMHP more generally. In particular, the collection of the Carers Star tool (by 70% of carers) at regular time points allows for outcomes of the FCMHP to be routinely measured.

The evaluation has analysed 16,540 data items/observations for 6,201 distinct carers who were supported by the five FCMHP CMOs across NSW between July 2018 and September 2020. This analysis shows that 80% of these 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 Carers Star data shows positive changes for carers across areas where support may have been needed over this period.

Stakeholder interviews have highlighted largely positive views of the FCMHP. The program is seen to be effective and meeting the needs of the carers who access it. Analysis indicates the program has improved the lives and wellbeing of carers, helped carers to better understand mental illness and how to care for their loved one and themselves. It has also helped to mend fractured relationships in families. Importantly, stakeholders highlighted 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.

Various opportunities to improve aspects of the FCMHP have been identified. It was noted that access to specific services varies between CMOs and LHDs. Similarly, services are not available in all areas within LHDs which presents access issues for some carers, especially those in rural or remote areas.

**Ongoing evaluation activities**

The second phase of the FCMHP evaluation will occur between March 2021 and September 2021 and build on the findings in this interim report. A second round of interviews will be conducted with the remaining LHDs, CMOs and other key stakeholders. In addition, we will conduct a survey of FCMHP consumers regarding their experiences of accessing the program. The FCMHP MDS data will be further analysed to better understand the effectiveness of the program. This will include assessing the association between carers demographic characteristics and the use of services, the effect of rural / urban location on the use of services, and further analyses of the outcomes of the program using longitudinal Carers Star data.

The final FCMHP evaluation report will synthesise all of the available data and include recommendations for consideration by the Ministry to support the ongoing implementation of the program.
1 Introduction

This is the interim report of the Family and Carer Mental Health Program (FCMHP) evaluation, prepared by the Centre for Health Service Development at the Australian Health Services Research Institute (University of Wollongong).

The FCMHP evaluation commenced in June 2020 and will conclude in September 2021. It is the first evaluation of the FCMHP program since it commenced in 2005. It has been commissioned by the Ministry to improve understanding of the achievements of the program and contribute to the evidence base for better supporting family and carers in providing support for people with mental health illness.

1.1 Purpose and scope of this report

The purpose of this interim report is to present a set of initial evaluation findings based on the data collection and related activities that have occurred to date. These include a document review, an analysis of FCMHP program data over a 12-year period and a thematic analysis of 15 initial FCMHP stakeholder interviews. Ongoing liaison with the Ministry and other stakeholders has also occurred throughout the evaluation.

It is important to note that the results presented in this report are interim and will be refined as the evaluation progresses. The methodology has been designed specifically to ensure that the interim findings and associated feedback informs the remainder of the evaluation. A comprehensive set of evaluation findings will then be provided in the final report in September 2021.

In this context, the scope of this interim report is to:

- Provide a brief background and history of the FCMHP;
- Present an analysis of FCMHP covering the period from November 2018 to December 2020;
- Present the results of a set of FCMHP stakeholder interviews conducted in November and December 2020; and
- Outline the activities that will occur during the remainder of the evaluation.
2 Background and context of the FCMHP

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

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

The FCMHP has two main program strategies. The first is to increase the capacity of the mental health service to work with families of clients with mental illness by:

- increasing the knowledge and skills of staff to work with families
- increasing organisational support to work with families
- developing / ensuring appropriate resources to work with families.

The second FCMHP strategy is to decrease the stress and burden of families of clients with a mental illness by:

- improving the initial linking/engagement of families with the service
- increasing the knowledge and skills of families
- increasing support for families.

2.1 A brief history of the FCMHP

A brief history of the FCMHP is included here to provide an historical context for the current evaluation. It is based on documentation provided by the Ministry and other FCMHP stakeholders. Some details included here are based on interviews with key stakeholders conducted as part of the first phase of the evaluation.

The Working With Families program, first established in 1996 at Sutherland Mental Health Service, aimed to increase the capacity of the Mental Health Service to work with families. In 2000, the NSW Caring for Carers Program funded nine mental health specific demonstration projects. As well, the ARAFMI Mapping Project and the Carers Life Course Framework project were funded to increase the knowledge about what is needed and what works in the local context. Building on these foundations, the Centre for Mental Health developed the Family and Carer Mental Health Program to provide education, support and partnerships with
families and carers and to promote family friendly culture and enable clinicians to work in a family/carer framework in adult mental health services across NSW.¹

The FCMHP also builds on strategic documents including *A New Direction for NSW State Health Plan Towards 2010*, the *NSW Carers Action Plan 2007-2012* and the *NSW: A new direction for mental health* plan. The program adopted the “Carers Compass” from King’s Fund, UK, as the core of the program.² As a part of the program, the Working With Families program conducted training for clinicians and mental health staff across NSW during 2004-2006. The Minister for Health officially launched the Program on 23 June 2005.

The program addresses the needs of families and carers via three linked components – LHDs, Non-Government Organisations (NGOs)³, and generic carer supports. The program funds only the first two components. State and federal sources fund mainstream support services.⁴ Figure 1 below provides an outline of the development of the FCMHP.

**Figure 1**  
**NSW Family and Carer Mental Health Program development⁵**

![Diagram of NSW Family and Carer Mental Health Program development](image)

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

³ Now referred to as Community Managed Organisations (CMOs).
The second key component was the funding of NGOs to provide direct support services for families and carers through NGOs. These NGOs were to work in partnership with Area Health Services, carers and families, and other external organisations to deliver services to family and carers. The Mental Health Drug and Alcohol branch within the Ministry also established a statewide steering committee to develop, implement and oversee the program.

Although the FCMHP was launched in 2005, disruptions caused by amalgamation of Area Health Services, and then again later by the restructuring into the current Local Health Districts, led to very limited progress generally with family friendly mental health services.

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

NGOs were contracted under the program to provide services to support families and carers. In the initial draft of the FCMHP Framework document, funding was provided to four NGOs to provide services in partnership with eight Area Health Services, as outlined in Table 1.

<table>
<thead>
<tr>
<th>NGO</th>
<th>Area Health Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schizophrenia Fellowship Carer Assist</td>
<td>Hunter New England, Greater Southern, Sydney South West</td>
</tr>
<tr>
<td>Carers NSW</td>
<td>Greater Western, North Coast, South East Sydney Illawarra</td>
</tr>
<tr>
<td>Uniting Care MH</td>
<td>Sydney West</td>
</tr>
<tr>
<td>ARAFMI NSW</td>
<td>North Sydney Central Coast</td>
</tr>
</tbody>
</table>

Services were retendered in 2011 and in the 2013 draft program structure outlined the five successful NGOs (now called Community Managed Organisations - CMOs) began providing services in partnership with 15 LHDs (Table 2).

<table>
<thead>
<tr>
<th>CMO (previously NGOs)</th>
<th>Local Health Districts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer Assist</td>
<td>Hunter New England, Southern NSW, Murrumbidgee, Sydney, South West Sydney</td>
</tr>
<tr>
<td>Centacare</td>
<td>Far West, Western</td>
</tr>
<tr>
<td>Aftercare</td>
<td>South East Sydney, Illawarra Shoalhaven</td>
</tr>
<tr>
<td>Uniting Care MH</td>
<td>Western Sydney, Nepean Blue Mountains, Central Coast, Northern Sydney</td>
</tr>
<tr>
<td>Mission Australia</td>
<td>Northern NSW, Mid North Coast</td>
</tr>
</tbody>
</table>

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In 2011, new agreements were signed after Area Health Services were amalgamated into Local Health Districts. New agreements were signed in 2013 with Key Performance Indicators (KPIs). These KPIs were updated in 2017-18 and again in 2020 after feedback from CMOs, to reflect populations in specific LHDs, such as Culturally and Linguistically Diverse (CALD) and Indigenous populations. A MDS was introduced in 2018 to provide consistent monitoring of CMO program activities. This was introduced in line with updated KPIs. The Carers Star tool was also introduced as a required carer assessment tool for CMOs, with data feeding into the MDS.

The earlier establishment in 2003 of a new data and monitoring unit in NSW Health, Information for Mental Health (InforMH), provided information for mental health service evaluation and development. Data from the MDS collected by CMOs and statistics produced by the LHDs under the FCMHP are forwarded to InforMH and included in state-wide reporting to inform service development. As such, the program includes a service development component and family engagement and support component.

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

Although the program is considered to be successful in its implementation and outcomes, the FCMHP has not previously been evaluated. To this end, the Mental Health Branch of the NSW Ministry of Health commissioned the Centre for Health Service Development, University of Wollongong to evaluate the program over 12 months from 1 July 2020 to 30 September 2021. The Mental Health Branch wishes to ensure the evaluation accurately reflects the positive impact of the program, while also identifying any areas for improvement and innovation.

### 2.1.1 Current structure and activity of the FCMHP

Under the current FCMHP arrangements, five CMOs deliver services across NSW with one responsible for each NSW LHD. Funding and Performance Agreements for the CMOs funded through the program are centrally managed by the Ministry. CMOs and LHDs negotiate Service Level Agreements to ensure an understanding of, and agreement to, the roles and responsibilities of all. The Service Level Agreements cover issues such as referrals, exchange of information, sharing resources, dispute resolution and risk management.

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

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LHDs and CMOs undertake different aspects of the FCMHP, although there is some degree of overlap. CMOs provide community based education and training programs to families and carers of those with a mental illness, individual support and advocacy services, and planning and infrastructure support for mental health-carer support groups.

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

Each LHD employs a Program Coordinator who provides clinical consultation and support to clinicians, families, carers and relevant partner organisations. This includes the provision of specialist interventions and education about mental health issues for families and carers, and the delivery of a wide range of initiatives for mental health staff and community partners.

The aim of these activities is to increase the skills and confidence of staff to work within a family and carer inclusive framework. FCMHP coordinators may or may not provide face-to-face services to carers, or may act as a coordinating role only, depending on their approach and level of resources with each LHD.

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

### 2.1.2 Justice Health and Forensic Mental Health Network

The Justice Health and Forensic Mental Health Network (JH&FMHN) is also part of the FCMHP. The JH&FMHN acts as its own Local Health District across all correctional mental health facilities within NSW and as such interacts with all CMOs contracted to the FCMHP through the JH&FMHN Family & Carer Consultant. The FCMHP Program Coordinator for the JH&FMHN is located within Long Bay Hospital.

MOUs enable the Program Coordinator to work with Justice Health to run workshops with carers and clinicians within the Justice Health system. Individual MOUs with CMOs and the
LHDs also facilitates individual support of carers, including face-to-face meetings. Education programs are provided to clinicians within the JH&FMHN in conjunction with carers from the custodial system and CMOs.

2.1.3 Culturally and linguistically diverse services

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

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

2.1.4 Policy and legislative framework

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

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

Subsequent amendments in 2014 provided an increased focus on the recovery of consumers, and further clarified and strengthened the role of carers. Chapter 4 of the Mental Health Act 2007 acknowledges that families and carers and the people they support have the right to be included in planning and decisions regarding all aspects of care and treatment. Constraints upon the disclosure of confidential medical information remain within the Act and other legislation, however, The Act clearly identifies the right of carers to be involved in their loved one’s care.  

At a national policy level, the National Mental Health Plan 2003-2008 contained key direction statements regarding families and carers in the specific context of mental health,

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10 New South Wales Parliament (2007) Mental Health Act 2007, Chapter 4, Part 1
including that supporting carers is the responsibility of all levels of governments and the community as a whole: “Mental health should be understood within a population health framework that takes into account the complex influences on mental health, (and) encourages a holistic approach to improving mental health and wellbeing”.  

At a state level, the policy underpinning the FCMHP includes a major ten-year reform agenda with a core focus of building an effective and integrated community support sector. The key policy document underpinning the expansion of the CMO-led and managed model of integrated care is the ‘Living Well: A Strategic Plan for Mental Health in NSW 2014 – 2024’. In this document, John Feneley, the NSW Mental Health Commissioner, states that the strategic plan provides the overarching ‘direction and principles for reform which agencies and service providers must find ways to embed in the supports they offer to people in the community’.

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

- The Carer Recognition Act 2010 and the NSW Carers Charter aims to increase recognition and awareness of carers and acknowledges the valuable contribution they make to society.
- Chapter 4 of the Mental Health Act 2007 acknowledges that families and carers and the people they support have the right to be included in planning and decisions regarding all aspects of care and treatment.
- Standard 2 of the National Safety and Quality Health Service Standards includes that families and carers and the people they support have the right to contribute to the improvement of mental health services.
- Standard 3 and Standard 7 of the National Standards for Mental Health Services 2010 also promotes consumer and carer participation in all aspects of care and treatment and the design and delivery of services.

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

2.1.5 Program theory underpinning the FCMHP

In a paper published in 2005, Mottaghipour and Bickerton found that there was no general framework for adult mental health professionals to incorporate families when working with patients with severe mental illness, in spite of its proven effectiveness in reducing patient

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relapse rate and family distress.\textsuperscript{15} The National Standards for Mental Health Services (1997) strongly recommended involving carers and patient families in mental health care partnerships.\textsuperscript{16} Mottaghipour and Bickerton argue that “the tasks of engaging, providing education and collaborating with families are well within the scope of an adult mental health worker”. With minimal extra training and a general framework, clinicians can incorporate family work in their everyday practice.

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

The Carers Compass\textsuperscript{17} is a central planning tool to help agencies develop their services. The Carers Star\textsuperscript{18} was added in 2018 as a service delivery and outcomes tool and covers seven key areas: Health, The Caring Role, Managing at Home, Time for yourself, How you feel, Finances and Work.

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

Outcome data collected from the Carers Star\textsuperscript{19} by CMOs is incorporated into the MDS sent to the Ministry of Health.

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

\textsuperscript{17} Banks P, Cheeseman C and Maggs S (1998) The Carers Compass: directions for improving support to carers, King’s Fund, UK.
\textsuperscript{19} Carers Star\textsuperscript{TM} © Triangle Consulting Social Enterprise Ltd. www.outcomesstar.org.uk.
The main resource for the program include the Connecting With Carers Is Everybody’s Business DVD and Handbook. This handbook includes an outline of the handbook for the Pyramid of Family Care (p. 6). The Pyramid has five levels:

- Connection and Assessment (Level 1)
- General Education
- Psychoeducation
- Consultation
- Family Therapy (Level 5).

The Pyramid of Family Care, as described by Mottaghipour and Bickerton in 2005, is used as a framework to guide family involvement. In their paper, they discuss a Pyramid of Family Care, based on the conceptual work of Maslow’s Hierarchy of Needs that starts with the family’s basic need for information up to the top level of complex needs. The underlying assumption is that basic needs must be met before higher needs. Within the Pyramid, a minimum level of care is outlined to guide the worker so that basic tasks and interventions are fulfilled before undertaking higher levels interventions for those who may need them, such as family therapy.

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

**Figure 2  Pyramid of Family Care**

Mottaghipour and colleagues also discuss a capacity-building framework comprised three components: increasing workforce knowledge and skills; increasing organisational support; and developing/ensuring appropriate resources.

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3 The FCMHP evaluation approach

A detailed outline of the FCMHP evaluation methodology was provided to the Ministry of Health in June 2020. In that document, we provided a detailed outline of our approach to each element of the evaluation. It included an overview of the framework that will underpin the evaluation, our approach to stakeholder engagement, data collection and data analysis activities.

The objective of the FCMHP evaluation is to assess the extent to which the model of care is effective, efficient and appropriate and what, if any, changes could be made to enhance its outcomes. The evaluation will identify issues and lessons that emerge and provide the Ministry with evidence on which to base decisions about its future development.

The key tasks of the FCMHP evaluation are to:

- 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 the 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 mental health services.

A sequential exploratory mixed methods approach is being adopted for the evaluation. This involves conducting initial data collection and analyses to develop a preliminary understanding of the program. The key findings from this initial phase (included in this interim report) will be used to inform the structure of the second phase of the evaluation. Importantly, the evaluation is not being approached with a sense of it being a ‘test’ which projects simply pass or fail. Rather, the evaluation is seen as developmental and a positive learning experience for the CMOs, the LHDs and the Ministry.

3.1 Key evaluation questions

The FCMHP evaluation is seeking to address the following key evaluation questions:

- Has the FCMHP been effective, efficient and appropriate and what, if any, changes could be made to enhance these outcomes?
- How well have resources have been targeted at the identified need and what, if any, changes could be made to enhance this?
- What the level of ‘value-add’ has been achieved in relation to improving partnerships with government, CMOs and other relevant stakeholders?

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Has there have been any unintended outcomes associated with the operation of the FCMHP?

3.2 Data sources

A comprehensive range of quantitative and qualitative data are being used in the FCMHP evaluation. This includes existing data where they have utility, along with a range of primary data collection activities being conducted at key points during the evaluation.

3.2.1 Quantitative data collection

Quantitative data have been provided by InforMH for the purposes of the evaluation. The primary data reported in this report are from the FCMHP MDS v1.0-v1.3 collected over the period July 2018 to September 2020. Additional data has also been provided from the previous FCMHP dataset (Versions 1 to 6) collected between October 2008 and June 2018.

3.2.2 Qualitative data collection

Qualitative data are being collected in two sequential phases through semi-structured interviews, surveys and focus groups. The first phase of the evaluation has involved an initial series of 15 interviews with key stakeholders from LHDs, CMOs and peak bodies/other stakeholders. The second phase will comprise a further round of stakeholder interviews, a consumer survey and potentially focus groups with FCMHP consumers. The qualitative data collection has and will continue to be affected by limitations associated with COVID-19.
4 Development of the FCMHP program logic

A program logic model 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 all 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, as 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.

It was agreed that the development of a model would be completed as part of the evaluation. Undertaking the retrofitting of a program logic provides additional opportunities to review the progress and achievements of the FCMHP\(^{23}\) as well as being a valuable resource for the program into the future.

Program logic development is an iterative process, involving consultation with relevant stakeholders. A draft FCMHP program logic model has been developed and is presented in Figure 3.

As the program logic has been developed retrospectively, the most current program framework information was used to source the overarching program outcome (shaded in blue) and the 14 program activities (shaded in dark blue) that have been included in the draft model.\(^{24}\) Our understanding is that this iteration of the framework was developed in 2017. The program inputs, other program outcomes, system level outcomes, and other contributing factors have been developed based on the Centre for Health Service Development’s understanding of the program at this time using the project information gathered to date.

Feedback on the draft program logic version will be sought to develop the final program logic model which will be included in the final evaluation report to be provided in September 2021.


Figure 3  FCMHP draft program logic

System level outcomes
- Cost benefits – reduction in readmissions, ED presentations, LOS etc.
- Improved awareness and understanding of the carer role to inform policy development, service planning, education etc.
- Compliance with legislative requirements

Program outcomes

Program outcomes
- Improving the wellbeing of families and carers of people living with mental health conditions, and the people they support

Mental health care services
- Improved provision of family friendly mental health services

Service access
- Improved coordination of support activities for families and carers
- More families and carers access appropriate and timely support and information services

Consumers
- Improved outcomes with the involvement of families and carers who are informed, supported and capable

Families and carers
- Improved understanding of and capacity to undertake their caring role

Other contributing factors
- Other mental health / carer support programs (community, state, Commonwealth)
- Other support services such as housing, financial assistance, counselling (community, state, Commonwealth)
- Peak bodies (advocacy and support activities)
- Mental health legislation / policy
- Mental health care provision to consumers
- Existing relationships and networks
- Clinician education (formal)

Activities

Developing services’ capability
- Providing training and professional development to public mental health service staff
- Providing consultation / supervision for public mental health service staff
- Providing relevant professional resources for public mental health service staff

Supporting families and carers
- Providing on- and off-site support and advocacy for carers
- Coordinating support groups for carers
- Supporting carers with additional needs and cultural diversity, and advocating on their behalf with relevant services and stakeholders
- Delivering internet / website and social media activities
- Delivering clinical services for families and carers and facilitating culturally responsive clinical practice

Informing families and carers
- Providing information and resources for carers
- Providing training / education programs for carers (including young carers) and organisations
- Delivering health promotion activities

Coordinating
- Strengthening referral and access pathways
- Supporting and coordinating carer participation and partnership activities (LHDs, CMOs and stakeholders)
- Planning and delivering LHD and CMO partnership activities

Funding from MoH / NSW LHDs / CMOs (x5) / MoH governance and support / Lived experience of carers/peer support / Statewide Network / Steering committees / FCMHP MDS

Evaluation of the NSW Family and Carer Mental Health Program: Interim Report – February 2021
5 Results: Quantitative data

The key aim of the quantitative analysis conducted in this initial stage of the evaluation was to quantify and delineate historical program activity. In this context, the results comprise two elements. The first is a detailed analysis of the FCMHP MDS covering the period July 2018 to September 2020. The second is an analysis of historical data pre-dating the introduction of the FCMHP MDS that covers the period 2008 to 2018.

The results are based on a secondary analysis of FCMHP MDS data collected by service providers as part of ongoing service provision. Definitions of the variables in the current and previous versions of the FCMHP MDS are provided at Appendix 1 and Appendix 2.

5.1 Overview of the FCMHP MDS data analysis

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).

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

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

The following analyses have been completed:

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

5.2 Demographic characteristics

Table 4 shows the demographic and referral source characteristics of carers who received support. The most common age group of carers was 50-59 across all CMOs except Catholic Care (40-49) where a higher proportion of carers aged less than 20 and over 80 were

25 The date from which the FCMHP MDS was introduced.
reported. Interestingly, almost 80% of carers across all CMOs were female. Around 14% of carers at Catholic Care (which services most remote areas of NSW) were from an Indigenous background while this proportion at the other CMOs was less than 6%. There was a wide variation in the sources of referral across CMOs, with two most common sources being ‘Self’ and ‘Public Mental Health Service referral’.

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

Table 4 Carers demographic and service characteristics (Jul 2018 to Sep 2020)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Stride (n=990) %</th>
<th>Catholic Care (n=475) %</th>
<th>Mission Australia (n=475) %</th>
<th>One Door (n=3,128) %</th>
<th>Parramatta Mission (n=1,133) %</th>
<th>Total (n=6,201) %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic</td>
<td></td>
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</table>

Referral source
## Level of support provided

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

### Individual support

Individual support captures direct time spent with carers and is recorded as ‘information’, ‘advocacy’, ‘emotional support’, ‘education and training’, and ‘referral’ activities. The number of carers receiving this support and the number of minutes reported against each category is shown in Table 5.

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

The ‘emotional support’ category had the largest number of reported minutes across CMOs (median 96, IQR: 45-223). Carers at Parramatta Mission received the highest amount

### Level of support provided

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Stride (n=990) %</th>
<th>Catholic Care (n=475) %</th>
<th>Mission Australia (n=475) %</th>
<th>One Door (n=3,128) %</th>
<th>Parramatta Mission (n=1,133) %</th>
<th>Total (n=6,201) %</th>
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<tr>
<td>Self</td>
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<td>34.3</td>
<td>24.1</td>
<td>60.6</td>
<td>32.1</td>
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<td>Family or Friend</td>
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<td>5.4</td>
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<td>39.1</td>
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<td>5.9</td>
<td>1.5</td>
<td>4.6</td>
<td>3.3</td>
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<td>Other Private Health Service</td>
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<td>16.6</td>
<td>10.2</td>
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<td>10.1</td>
</tr>
<tr>
<td>CMO (Same Provider)</td>
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<td>2.3</td>
<td>0.8</td>
<td>1.7</td>
<td>1.6</td>
</tr>
<tr>
<td>Other</td>
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<td>5.3</td>
<td>5.7</td>
<td>1.9</td>
<td>3.7</td>
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<td>1.1</td>
<td>1.1</td>
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### Refer to other services

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</tr>
</thead>
<tbody>
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<td></td>
<td>40.6</td>
<td>59.4</td>
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### Visit Community Services

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<th>Visit Community Services</th>
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</thead>
<tbody>
<tr>
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<td>25.7</td>
<td>74.3</td>
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</table>

### Carers Star Chart completed

<table>
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<tr>
<th>Carers Star Chart completed</th>
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<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>59.5</td>
<td>40.5</td>
</tr>
</tbody>
</table>

---

5.3.1 Individual support

Individual support captures direct time spent with carers and is recorded as ‘information’, ‘advocacy’, ‘emotional support’, ‘education and training’, and ‘referral’ activities. The number of carers receiving this support and the number of minutes reported against each category is shown in Table 5.

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

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

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

Overall, 20% of carers received ‘education and training’ support, but this also varied widely by CMO ranging from only 1% at Mission Australia to 27% at One Door. The median time spent on education and training was almost 30 minutes (IQR: 15-34) minutes across CMOs. Catholic Care provided the largest number of minutes on this support activity (median time: 120 minutes, IQR: 20-420).

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

Table 5 Minutes of individual support (Jul 2018 to Sep 2020)

<table>
<thead>
<tr>
<th>Types of support</th>
<th>Stride (n=990)</th>
<th>Catholic Care (n=475)</th>
<th>Mission Australia (n=475)</th>
<th>One Door (n=3,128)</th>
<th>Parramatta Mission (n=1,133)</th>
<th>Total (n=6,201)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information n (%)</td>
<td>954 (96%)</td>
<td>435 (92%)</td>
<td>99 (21%)</td>
<td>2262 (72%)</td>
<td>1109 (98%)</td>
<td>5259 (85%)</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>63 (30-134)</td>
<td>75 (30-138)</td>
<td>40 (20-70)</td>
<td>60 (30-124)</td>
<td>209 (82-477)</td>
<td>80 (34-183)</td>
</tr>
<tr>
<td>Advocacy n (%)</td>
<td>161 (16%)</td>
<td>117 (25%)</td>
<td>100 (21%)</td>
<td>987 (32%)</td>
<td>131 (12%)</td>
<td>1496 (24%)</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>32 (15-72)</td>
<td>50 (20-120)</td>
<td>33 (30-60)</td>
<td>45 (20-95)</td>
<td>37 (15-90)</td>
<td>42 (20-90)</td>
</tr>
<tr>
<td>Emotional n (%)</td>
<td>834 (84%)</td>
<td>347 (73%)</td>
<td>378 (80%)</td>
<td>2484 (79%)</td>
<td>873 (77%)</td>
<td>4916 (79%)</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>81 (33-164)</td>
<td>140 (65-375)</td>
<td>135 (65-285)</td>
<td>75 (40-150)</td>
<td>238 (93-595)</td>
<td>96 (45-223)</td>
</tr>
<tr>
<td>Education and training n (%)</td>
<td>228 (23%)</td>
<td>68 (14%)</td>
<td>6 (1%)</td>
<td>833 (27%)</td>
<td>127 (11%)</td>
<td>1262 (20%)</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>28 (14-60)</td>
<td>120 (20-420)</td>
<td>30 (15-40)</td>
<td>30 (15-79)</td>
<td>22 (15-45)</td>
<td>30 (15-74)</td>
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<tr>
<td>Referral n (%)</td>
<td>486 (49%)</td>
<td>136 (29%)</td>
<td>54 (11%)</td>
<td>1284 (41%)</td>
<td>477 (42%)</td>
<td>2437 (39%)</td>
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<tr>
<td>Median (IQR)</td>
<td>21 (12-36)</td>
<td>40 (20-105)</td>
<td>30 (15-30)</td>
<td>25 (15-45)</td>
<td>30 (15-52)</td>
<td>25 (15-45)</td>
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</table>
5.3.2 Group support

Group support captures time spent with carers who attend ‘information sessions’, education/training courses’ and ‘support groups’. Time reported against each category by CMO is shown in Table 6. A substantial proportion of carers at Catholic Care (32%) and Parramatta Mission (39%) had ‘information’ reported on a group basis, with median number of minutes reported as 90 (IQR: 10-240) and 105 (IQR: 45-300) respectively. In contrast, a much lower proportion of carers at One Door (5%), Mission Australian (9%) and Stride (13%) had this activity category recorded.

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

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

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

<table>
<thead>
<tr>
<th>Types of support</th>
<th>Stride (n=990)</th>
<th>Catholic Care (n=475)</th>
<th>Mission Australia (n=475)</th>
<th>One Door (n=3128)</th>
<th>Parramatta Mission (n=1,133)</th>
<th>Total (n=6201)</th>
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<tbody>
<tr>
<td>Information</td>
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<tr>
<td>n (%)</td>
<td>133 (13%)</td>
<td>150 (32%)</td>
<td>41 (9%)</td>
<td>142 (5%)</td>
<td>441 (39%)</td>
<td>907 (15%)</td>
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<td>Median (IQR)</td>
<td>168 (36-435)</td>
<td>90 (10-240)</td>
<td>240 (180-330)</td>
<td>120 (60-210)</td>
<td>105 (45-300)</td>
<td>120 (45-307)</td>
</tr>
<tr>
<td>Education and training</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n (%)</td>
<td>222 (22%)</td>
<td>127 (27%)</td>
<td>255 (54%)</td>
<td>737 (24%)</td>
<td>371 (33%)</td>
<td>1712 (28%)</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>420 (312-904)</td>
<td>240 (120-605)</td>
<td>440 (180-840)</td>
<td>240 (180-540)</td>
<td>390 (240-930)</td>
<td>360 (180-720)</td>
</tr>
<tr>
<td>Support group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n (%)</td>
<td>271 (27%)</td>
<td>140 (29%)</td>
<td>184 (39%)</td>
<td>524 (17%)</td>
<td>413 (36%)</td>
<td>1532 (25%)</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>418 (158-1320)</td>
<td>380 (140-699)</td>
<td>415 (145-840)</td>
<td>240 (120-521)</td>
<td>247 (120-660)</td>
<td>299 (135-710)</td>
</tr>
</tbody>
</table>
5.3.3 Indirect support

Indirect support captures time spent on carer administration (e.g. making bookings or spending time to research service options) and time spent on travel to and from a carer to provide support. Time reported against each category by CMO is shown in Table 7. Most carers at One Door (95%) and Stride (89%) had time recorded against this activity with a median of 60 minutes (IQR: 30-120) and 73 minutes (IQR: 27-225), respectively. Almost half of the carers at Parramatta Mission had time recorded against this activity, with the highest median of 193 minutes (IQR: 90-405).

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

Table 7 Minutes of indirect support (Jul 2018 to Sep 2020)

<table>
<thead>
<tr>
<th>Types of support</th>
<th>Stride (n=990)</th>
<th>Catholic Care (n=475)</th>
<th>Mission Australia (n=475)</th>
<th>One Door (n=3128)</th>
<th>Parramatta Mission (n=1133)</th>
<th>Total (n=6201)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program admin</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n (%)</td>
<td>878 (89%)</td>
<td>147 (31%)</td>
<td>217 (46%)</td>
<td>2972 (95%)</td>
<td>571 (50%)</td>
<td>4785 (77%)</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>73</td>
<td>45 (27-225)</td>
<td>50 (30-110)</td>
<td>60 (30-120)</td>
<td>193 (90-405)</td>
<td>65 (30-150)</td>
</tr>
<tr>
<td>Travel to and from carer</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n (%)</td>
<td>436 (44%)</td>
<td>147 (31%)</td>
<td>152 (32%)</td>
<td>780 (25%)</td>
<td>515 (45%)</td>
<td>2030 (33%)</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>90</td>
<td>180 (30-380)</td>
<td>120 (60-297)</td>
<td>40 (20-75)</td>
<td>145 (60-350)</td>
<td>75 (30-195)</td>
</tr>
</tbody>
</table>

5.4 Longitudinal analysis of Carers Star outcomes

The Carers Star outcomes tool enables organisations to measure and summarise changes made by people with different needs. It comprises seven domains: ‘Health’, ‘The caring role’, ‘Managing at home’, ‘Time for yourself’, ‘How you feel’, ‘Finance’ 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’.

Almost 71% (n=4,372) of carers for whom data were available (n=6,201) completed the tool at least once between July 2018 and September 2020. A substantial proportion of carers completed the Carers Star more than once, with 36% (n=2,219) two or more times, 20% (n=1,291) three or more times, 14% (n=873) four or more times and 10% (n=622) five or more times. A longitudinal analysis of the tool is presented below for the six domains where data were available.
5.4.1 Carers Star: ‘Health’ domain

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

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

5.4.2 Carers Star: ‘The caring role’ domain

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

Figure 6 shows changes in scores for the Carers Star ‘caring role’ domain across eight (or more) time points between July 2018 and October 2020. This domain showed relatively little overall change over the period, other than a moderate increase in the proportion of carers reporting ‘as good as it can be’ or ‘mostly OK’ in the second and third time points. However, this was not surprising given that the majority of carers (62%) 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.
5.4.4 Carers Star: ‘Time for yourself’ domain

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

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

5.4.5 Carers Star: ‘How you feel’ domain

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

5.4.6 Carers Star: ‘Finance’ domain

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

Figure 9  Changes in Carers Star ‘Finance’ domain (Jul 2018 to Sep 2020)
5.5 Historical FCMHP data

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 datasets were routinely collected by CMOs between 2008 and 2018 through a process managed by external consultants.

The Ministry holds the data collected in FCMHP MDS Versions 1 to 6. However, the data are less complete and generally of a much lower quality than the current FCMHP MDS. The evaluation was provided with the following data extracted from these datasets:

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

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

5.5.1 Registered clients and consumers data

The demographic profile of carers who received services during this period is shown at Table 8. Over the different reporting periods between October 2008 to June 2018, a total of 16,506 clients were registered by seven CMOs comprising Aftercare (10%), Arafmi (3%), Care Assist (51%), Carers NSW (10%), Centre Care (7%), Mission Australia (7%) and Uniting Care Mental Health (12%).

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

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

The consumer data consisted of 18,423 consumers who had been cared/supported by 15,990 carers. The majority of consumers were cared by parents (53%), followed by partner (19%), child (11%) and sibling (7%). Almost, two-thirds of consumers lived with their carers (65%).
### Table 8  Carer demographic characteristics (Oct 2008 and Jun 2018)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Number of carers n=16,506</th>
<th>Percentage %</th>
<th>Characteristics</th>
<th>Number of carers n=16,506</th>
<th>Percentage %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name of the CMO</td>
<td></td>
<td></td>
<td>CALD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aftercare</td>
<td>1703</td>
<td>10.3</td>
<td>Yes</td>
<td>2540</td>
<td>18.0</td>
</tr>
<tr>
<td>Arafmi</td>
<td>456</td>
<td>2.8</td>
<td>No</td>
<td>11060</td>
<td>78.3</td>
</tr>
<tr>
<td>Carer Assist</td>
<td>8442</td>
<td>51.2</td>
<td>How long in caring role</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carers NSW</td>
<td>1645</td>
<td>10.0</td>
<td>0</td>
<td>59</td>
<td>0.4</td>
</tr>
<tr>
<td>Centre Care</td>
<td>1064</td>
<td>6.5</td>
<td>≤ 6 months</td>
<td>1177</td>
<td>7.7</td>
</tr>
<tr>
<td>Mission Australia</td>
<td>1144</td>
<td>6.9</td>
<td>6 months - 1 year</td>
<td>1944</td>
<td>12.7</td>
</tr>
<tr>
<td>Uniting Care mental Health</td>
<td>2052</td>
<td>12.4</td>
<td>2-5 years</td>
<td>4463</td>
<td>29.0</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td>6-10 years</td>
<td>3050</td>
<td>19.8</td>
</tr>
<tr>
<td>Female</td>
<td>11987</td>
<td>76.0</td>
<td>11-20 years</td>
<td>2754</td>
<td>17.9</td>
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<tr>
<td>Male</td>
<td>3722</td>
<td>23.6</td>
<td>Employment status</td>
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<td>Not stated</td>
<td>58</td>
<td>0.4</td>
<td>Full-time</td>
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<td>21.7</td>
</tr>
<tr>
<td>Age group</td>
<td></td>
<td></td>
<td>Part-time</td>
<td>2390</td>
<td>15.8</td>
</tr>
<tr>
<td>less than 20</td>
<td>566</td>
<td>4.6</td>
<td>Casual</td>
<td>904</td>
<td>6.0</td>
</tr>
<tr>
<td>20-29</td>
<td>597</td>
<td>4.9</td>
<td>Unemployed</td>
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<td>19.2</td>
</tr>
<tr>
<td>30-39</td>
<td>1303</td>
<td>10.7</td>
<td>Retired or not in labour force</td>
<td>5673</td>
<td>37.4</td>
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<td>40-49</td>
<td>2527</td>
<td>20.7</td>
<td>Initial client needs</td>
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<td>50-59</td>
<td>3315</td>
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<td>Information</td>
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<td>60-69</td>
<td>2552</td>
<td>20.9</td>
<td>Emotional</td>
<td>11125</td>
<td>67.4</td>
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<td>70-79</td>
<td>1086</td>
<td>8.9</td>
<td>Education</td>
<td>6709</td>
<td>40.7</td>
</tr>
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<td>80 and over</td>
<td>241</td>
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<td>Advocacy</td>
<td>3427</td>
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<td>Language speaking at home</td>
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<td>Referral</td>
<td>3187</td>
<td>19.31</td>
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<td>English</td>
<td>14007</td>
<td>90.9</td>
<td>Number of people cared for</td>
<td></td>
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<td>Non-English</td>
<td>1399</td>
<td>9.1</td>
<td>1</td>
<td>13439</td>
<td>88.5</td>
</tr>
<tr>
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<td>More than 2</td>
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<td>Non-Indigenous</td>
<td>11321</td>
<td>86.0</td>
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</tr>
</tbody>
</table>

#### 5.5.2 Contacts and service data

A total of 330,513 records of contacts and services were observed for carers who received assistance between October 2008 and June 2018. Around 74% of contacts and services data (n=223,588) were for registered clients, and 26% (n=78,793) were for non-registered clients excluding 28,133 missing information (Table 9). However, nearly one third of contacts and services data (n=104,648) did not have any client ID and so the number of distinct carers is unknown. The contacts and service data (n=225,866) which have a carer ID were reported by
20,503 distinct carers of which 15,141 carers also included in the registered clients and consumers data sets described earlier.

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

### Table 9   Number of contacts and services (Oct 2008 to Jun 2020)

<table>
<thead>
<tr>
<th>Year</th>
<th>Reporting period</th>
<th>Number of contacts and services</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Registered clients</td>
<td>Non registered clients</td>
</tr>
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<td>2008</td>
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<td>3</td>
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</tr>
<tr>
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<td>5</td>
<td>3466</td>
<td>1922</td>
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<td>5007</td>
<td>1776</td>
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<tr>
<td></td>
<td>7</td>
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<td>1019</td>
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<td>4025</td>
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<td>5340</td>
<td>2842</td>
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<td>2013</td>
<td>18</td>
<td>5622</td>
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<td>8720</td>
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</tr>
<tr>
<td>2016</td>
<td>30</td>
<td>6344</td>
<td>2980</td>
</tr>
</tbody>
</table>
5.5.3 DASS assessment data

A total of 13,811 assessments were completed between October 2008 and June 2018, using the Depression Anxiety and Stress Scale-42 (DASS-42). The majority of the assessments were completed at the initial stage (58%, n=7,937) and 42% (n=5,785) was completed at follow-up (Table 10). 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 10). 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 10 DASS initial assessment and follow-up scores

<table>
<thead>
<tr>
<th>DASS Assessment</th>
<th>Initial assessment (n=7,937)</th>
<th>Follow-up (n=5,785)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>Standard deviation</td>
</tr>
<tr>
<td>Depression</td>
<td>13.5</td>
<td>10.9</td>
</tr>
<tr>
<td>Anxiety</td>
<td>10.4</td>
<td>9.6</td>
</tr>
<tr>
<td>Stress</td>
<td>17.8</td>
<td>10.5</td>
</tr>
</tbody>
</table>

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

5.5.4 Support group, education/training and Information session data

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

The number of registered carers that participated in these sessions was 7,199. However, the data also included 7,822 non-registered carers and 6,833 carers that could not be linked to the activity data. Overall, this dataset is not considered to be of sufficient quality to conduct any further analysis regarding participants’ characteristics or completed activities.
6 Results: Qualitative data

The key aim of the qualitative analysis conducted in this initial stage of the evaluation was to identify the barriers and enabling factors that have influenced the FCMHP as a whole. Fifteen individuals from key FCMHP stakeholder organisations participated in an interview for the initial phase of the evaluation between 27 October and 27 November 2020. The breakdown of the organisations represented by the individuals interviewed is shown in Table 11.

<table>
<thead>
<tr>
<th>Organisation/group</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Local Health Districts (LHDs)</td>
<td>6</td>
</tr>
<tr>
<td>▪ Far West</td>
<td></td>
</tr>
<tr>
<td>▪ Hunter New England</td>
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The interviews were semi-structured and took on average between 30 - 45 minutes to complete. The interview questions for the CMOs, LHDs and other stakeholders differed slightly and are shown at Appendix 3 to Appendix 5. 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.

The analysis of the interview data applied on 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.\(^{26}\) It enables the raw data to be

summarised and sorted for analysis according to the different themes that emerge both within and across interviews.

The thematic analysis of the interviews have been structured around three broad subject areas:

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

6.1 Service effectiveness and meeting needs

In general, the program is seen to be effective and to meet the needs of the carers who access it. The program has improved the lives and wellbeing of carers, helped carers to better understand mental illness and how to care for their loved one and themselves and has helped to mend fractured relationships in families. The program has also contributed to changes in practice and culture in mental health services towards more inclusive, systemic approaches. Some participants believe the program would have an impact on emergency department presentations and hospitalisation.

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

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

Elements of effectiveness have included clear structures or guidelines, room for flexibility to allow for local practices and innovation and building partnerships.

Carers appear to be well engaged in the program with some accessing the service for more than 12 months. Feedback from carers has indicated high family carer satisfaction with the program, including that program staff understand carer needs, are good at engaging carers and at working with complexity.

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

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

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

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

The program provides practical support to carers to access other services such as Centrelink. Service providers work with carers ‘walking them through’ the referral processes, building on relationships that they have made with referral agencies. Examples of support include making the call or being present when the call is made and going with the carer to the first appointment.

The program is seen to increase the capacity of carers to care for their loved ones through information education sessions about mental illness, recovery, medication, etc. Carer capacity is also built through attending case meetings, being more engaged with the treating team – overall being more actively involved in the consumer’s care. Supporting the carer’s wellbeing also allows them to better care for their loved ones. The program has assisted family and carers to improve their relationship with their loved one through information, training and mediation processes.

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

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

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

Participants reported some issues with access and variance in service delivery with specific services offered on the program varying between CMOs and LHDs. Geographically, services are not available in all areas within LHDs, which presents access issues for some carers,
especially those in rural or remote LHDs with large geographical coverage. Some LHDs are increasing access through telehealth however this is not seen as being as effective at engaging or supporting carers as face-to-face services.

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 as.

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

### 6.1.1 Meeting the needs of marginalised and/or minority groups

**Aboriginal and Torres Strait Islander people**

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

*I don’t think we do well at understanding what a carer role might be in an Aboriginal family, if that’s even the language that’s used. .... but, again, because we don’t have expertise or enough understanding about how we could maybe be working better with our, and I’ll use again, our Aboriginal and Torres Strait Islander communities I think our stakeholder relationships there are also lacking, because we’re not even confident in how we would approach that. We need that learning.* (CMO)

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

*I would definitely love to see culturally informed practice built into family and carers program. I would like to have that done through Aboriginal voices in the service design, and helping to have a look at how the program could be adapted, I guess, to better reach out to and engage Aboriginal and Torres Strait Islander carers and families. But also just families from cultural and linguistically diverse backgrounds that are in our program.* (CMO)

**Culturally and linguistically diverse groups**

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

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

... definitely, the service of the FCMHP are more effective for carer from English speaking [countries]. ... They can easily access the service, in terms of, for CALD carers, apart from receiving psycho-education, while participating in our carer support group, our language is specific carer support group, so apart from receiving psycho-education through our carer support group they can't actually participate in the carer education that is run in English. ... sometimes they have the right staff who speak the language, but if they don't it's really difficult. (Statewide Stakeholder)

Young carer and male carers

While there are a number of initiatives underway to increase engagement, young carers and male carers are largely underrepresented in the program. When they do access the program, the support is often not well tailored to their needs.

I think on the whole, the people ... Well, people in our youth and family teams are very good at connecting with families. ... I think that we don't do so well with young carers. ... when our CMO here gets families or they're aware of young people, then they will dive into that and explore and see what support can be offered but I think on the whole, our young carers don't get as much as they could. (LHD)

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

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

We've introduced a peer worker, which is the male worker. And he comes from a background of being a young carer. So he works with our program and he has brought such a different dimension to our program. So he works with the young people, and with male carers as well. So that's been great. (CMO)
So we have a relationship with the schooling coordinator. ... we've got a relationship with headspace as well in our regions, and so we do get referrals that way as well. (CMO)

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

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

6.1.2 Culture change

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

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

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

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

I think the other thing as far as for the service providers or healthcare system, if we didn't have these programs entrenched within our organisations, the families would fall off the radar. I could promise you that 100%. In fact, we know that there are still big pockets where the families or the carers aren't considered, because there aren't enough of us within the Family and Carer Program to ensure that it's always on everybody's radar. (CMO)
Every time they’re talking about a consumer, what about the carer? What about the family? What’s happening there? We can’t be everything to everyone, so we have to rely on some of the champions that would be within our service that do work family-inclusively to model that for their colleagues. (LHD)

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

### 6.1.3 Elements of effectiveness

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

**Structure**

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

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

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

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

**Flexible practices and processes**

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

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

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

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

Partnerships

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

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

Most participants have found collaboration between LHDs useful and would like more opportunities to share local innovations, locally developed processes and tools. As program staff have identified and built rapport with support services in the community, the program has increased access to carers to other services beyond the LHDs.

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

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

6.1.4 Family inclusive services

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

The program offers one on one support and group training aimed at helping carers understand their rights and support their involvement in the care of their loved one.
The one-to-one support, I think helps people understand their rights as a carer to learn what questions to ask, when they’re with clinicians. To know that they can have a right to be involved with discharge planning and care plans and things like that. (CMO)

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

According to participants, carers are now ‘at the table’ (LHD) rather than ‘on the periphery’.

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

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

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

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

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

6.1.5 Participation in program and service delivery

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

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

Many of these roles have a co-design component where carers work directly with clinicians to design programs and education and promotion resources. In one LHD, carers are supported by the program, working together with program staff and clinicians to develop processes to improve family inclusive practices within the program and the services the program supports.
We've got the family carer action group, which we've set up, which is clinicians and family care participants together, sort of working on initiatives to improve family inclusive practice and looking at gaps and how we can be doing things more in a co-design sort of way. (LHD)

Systems change more widely

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

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

Valuing carer participation

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

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

Enablers

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

Educating carers on their rights and supporting carers to participate

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

We promote there's a carer charter of rights, I think on the NSW Health website, it talks about what the care rights are. I think we do try to encourage people to make sure that they're aware of that and what they can do. (CMO)
Executive support was seen as an important element of success. Participants reported that in areas where the executive really understood, believed or ‘championed’ carer participation was much more embedded in service delivery. Executive support also facilitated carer inclusion in governance and accountability processes (e.g. KPIs).

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

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

I started in 2006, so just before the program started in mental health. I have noticed a huge change in the culture around inclusion of families, and in particular, now more so even from our psychological and our psychiatry staff. (LHD)

Breaking down stigma

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

Carers themselves might have pre-conceived ideas about mental illness and the clinical environment. The program is breaking down some of the stigma and fear carers might have about mental health and the mental health system, helping carers to feel safe, comfortable and welcome in mental health spaces.

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

Challenges to carer inclusion

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

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

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

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

Tensions between consumer and carer perspectives

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

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

It’s about helping families understand, the system isn’t against you. You just need to understand how to work with us in the system, and with your person in the system, so that everyone has their needs met, and nobody feels like they’re being left out. (LHD)

6.2 Current program structure, funding and governance arrangements

The current structure of the FCMHP is largely considered to be effective. Under the current arrangements, most FCMHP funding is allocated to five CMOs who deliver services across all LHDs and the JH&FMHN. A much smaller level of funding is allocated to LHDs to employ a
Program Coordinator who provides clinical consultation and support to clinicians, families, carers and relevant partner organisations.

LHDs are largely autonomous in determining their approach to delivering FCMHP services. This is reflected in the very 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. At the same time, participants felt that a more structured and coordinated approach may reach more carers, particularly in rural and remote areas. It was suggested that ideally LHDs could employ a clinical lead that has direct access to a larger workforce. The fundamental importance of executive level support for the program was identified in this context.

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

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

The current FCMHP structure for CMOs was supported by participants. Some would like to provide sessions of family therapy. Others spoke about filling gaps in providing services to carers who work through out of office hours activities, such as evening support groups. The effectiveness of face-to-face events in which carers are able to speak and clinicians can learn about the carer experience were seen as particularly valuable.

The level of overall program resources emerged as a key issue. The lack of resources was seen as the key factor limiting the opportunities to build partnerships and capacity within the program. For LHD staff, this often results in the need to ‘ration’ the level of support provided to carers or risk staff burnout. For example, one participant focused on the need for more peer care workers to ease the workload for clinicians and for health workers in general.

> So whilst the clinicians working with the person then the carer peer worker could work with the family members who are around. I think that would really shift things. I do think it’s a resourcing issue overall. I think they get it, I think they get the importance of carers but I think that the workloads are just so massive. (LHD)
Support for carers in crisis was a theme, including carers from the correctional system, and providing support to carers in a way that is sensitive to their situation. Employing peer workers through the system was also seen as very important. In addition, engagement between community health services and the FCMHP was identified as an area of need.

6.2.1 Justice Health and Forensic Mental Health Network

The FCMHP operates within different parameters in the JH&FMHN. The JH&FMHN is a specialist network within the NSW public health system and as such works with all CMOs. Unlike the LHDs, the JH&FMHN has a range of restrictions in its operations that can make it difficult for families and carers of patients within this system. The Program Coordinator works within an MOU between the FCMHP and Justice Health that allows for workshops with carers and clinicians. Individual MOUs with CMOs and the eight LHDs also facilitates individual support of carers, including face-to-face meetings.

With only one worker to coordinate the FCMHP within the JH&FMHN, the program is relatively small. Education programs are provided to clinicians within the JH&FMHN in conjunction with carers from the custodial system. These carers are paid for the time spent undertaking these activities. CMOs are included in providing clinician training. The greatest benefit to the clinician is when they hear from the carer, however, clinician attendance at training is often reliant on good leadership. While some clinicians do engage with the program, a negative view of patients and their families is still a barrier for some clinicians making referrals to the program.

The FCMHP Coordinator for also works with JH&FMHN carers, including face-to-face meetings. In regards to being able to refer carers of individuals in the forensic and justice systems to FCMHP services, it can be very “hit and miss” in spite of the education provided to staff. The majority of families are referred by a CMO to the FCMHP at Justice Health. There are some clinicians in the forensic system who will also refer to the program but there are still barriers with some clinicians who have a negative view of patients and carers in the Forensic and Custodial system.

6.2.2 CALD program

The TMHC Carer Program is a small program that reaches out to CALD carers and family under the FCMHP. The program is limited to the Sydney metropolitan area providing information and support. Funding covers the Program Coordinator wage, sessional bilingual leaders and training of bilingual workers. There are currently 11 bilingual workers running 14 carer support groups in 10 different languages.

Groups are run in all five Sydney LHDs but predominantly in South Western Sydney. They work with carers to link them to organisations, e.g. the NDIS and Carer Gateway, and enable CALD carers to access information without language and cultural barriers. The TMHC Program adopted the bilingual worker model from Women’s and Refugee Health, to deliver health services to refugee populations. The Program Manager indicated that some LHDs need more bilingual care workers due to population expansion. A lack of resources has meant fewer trained CALD support workers, leaving non-English speaking carers unable to access support in their language.
At the moment, those carer’s education and training are locked in each LHD, and only English speaking carers can access. Carers from CALD background can’t use it. (CMO)

This is also a difficulty for carers accessing the Carer Gateway and NDIS services, something that the Program Manager and support staff spend time helping CALD carers navigate.

6.2.3 KPIs and data collection

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

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

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

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

6.3 Effects of the COVID-19 pandemic

There were positive and negative impacts on the program from the COVID-19 pandemic and the associated restrictions. The services consistently demonstrated that they were able to be creative and flexible and respond quickly to the changing environment. This meant that the program continued to operate, albeit with the many changes which were implemented in response to the conditions imposed on both providers and carers.

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

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. There was also a fear amongst carers around presenting to health services such as emergency departments. A further concern was the lack of a ‘safe space’ for carers to talk openly about their issues, including as part of the carer assessment process.

_We just tried to really be there. Our emotional support really increased during that time. It was massive._ (CMO)
Increasing use of the telephone and online technology to engage with carers, such as digital platforms for social events, education sessions, meetings, and the provision of links to additional resources, had the benefit of improving access opportunities for some carers. Issues such as remoteness, travel costs, work commitments, and being unable to be away from home had previously presented barriers to program involvement.

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

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

Overall, there were positive learnings from the adjustment to the pandemic conditions, and some innovations that were implemented are seen as ongoing opportunities to enhance the program. At the same time, COVID-19 has resulted in less access to the program for some carers and there is an increasingly general sense of fatigue with the need to rely on online services. The provision of face-to-face contact is considered to be essential into the future.

You get the carers that really miss that connection of seeing somebody. They’re like, ‘Look, we can’t sit in an office together. But let’s meet in the park and we can walk and talk together’. (CMO)

There was a decrease in the number of referrals in some services, while others experienced an increase during this period. Services have been returning to more normal operations as restrictions ease, with the longer term impacts from the pandemic not clear at this time.

I think our experience is probably reflecting the wider community, and there are positives and we can learn from COVID and there are negatives and hopefully that’ll resolve. (LHD)


7 Discussion

Carers have a critical role to play in providing support for people with mental health illness. The FCMHP is a key program funded by the Ministry that aims to improve the wellbeing of families and carers of people with mental health conditions and the people they support. The program acknowledges the critical role families and carers play in promoting and sustaining positive mental health and recovery, together with consumers, practitioners and relevant professionals.

The FCMHP has not been evaluated since its inception in 2005. However, it has been widely regarded as an important and successful initiative. The key aim of the evaluation is to assess the extent to which the model of care is effective, efficient and appropriate and what, if any, changes could be made to enhance its outcomes.

A range of important findings have emerged in the FCMHP evaluation to date. The program is broadly accepted by its stakeholders and is seen to be effective in meeting the needs and improving the lives of carers. Importantly stakeholders highlighted 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.

The implementation of a FCMHP MDS in 2018 with the inclusion of the Carers Star tool has been an important development for the program. It provides a scientific basis for understanding the programs outcomes including being able to measure changes among carers over time. A longitudinal analysis of the FCMHP Carers Star data shows positive changes for carers across each of the areas where support may have been needed.

An analysis of 16,540 data items/observations for 6,201 distinct carers between July 2018 and October 2020 supports the finding that the program has been effective in terms of its reach. On average, carers received 180 minutes of individual care, 380 minutes of group care and 81 minutes of indirect care over the analysis period.

The demographic profile of carers, showing that 80% are female and aged over 40 is consistent with previous research in this area. Importantly, FCMHP stakeholders identified ways to increase engagement and tailor appropriate support to young people and males. These include the employment of male carer peer workers, building relationships with organisations that work with these groups and running groups that are specific to these cohorts. Other suggestions for improvement were to increase access for the Aboriginal and Torres Strait Islander population by 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 the FCMHP model of care and services delivery structures, the program appears to largely embracing principles that have been shown to be associated with successful carer programs. This includes flexible approaches and tailored family interventions that are part of usual service provision. At the same time, participants reported that while there have been
significant increases in carer inclusion, there is some way to go before carer inclusion is fully embedded in services.

**Program logic**

A key output of the evaluation to date is the development of a draft FCMHP program logic. It aims to provide a chain of logic linking FCMHP resources and inputs to outputs and anticipated outcomes. It is our hope that the FCMHP program logic will assist in identifying essential elements of the program, provide a framework for monitoring and reporting, and strengthen future evaluation evidence.

**Next steps for the FCMHP evaluation**

The second phase of the FCMHP evaluation will occur between March and September 2021 and will build on this interim report. A second round of interviews will be conducted with the remaining LHDs, CMOs and targeted stakeholders. In addition, we will conduct a survey of FCMHP consumers regarding their experiences of accessing the program.

The evaluation will not access any additional FCMHP MDS data. The data provided by InforMH to date is more than sufficient to complete a series of further analyses to better understand the effectiveness of the program. This will include examining the association between carers demographics and the use of services over time, the effect of rural / urban location on the use of services, and further analyses of the outcomes of the program using longitudinal Carers Star data.

The final FCMHP evaluation report will synthesise all data and present a set of findings that specifically address the evaluation questions. This will include a set of recommendations for consideration by the Ministry to support the ongoing implementation of the program.
### Appendix 1  Draft FCMHP Minimum Data Set specification (V1.3)

<table>
<thead>
<tr>
<th>Itemno.</th>
<th>Data item</th>
<th>Field header</th>
<th>Metadata definition</th>
<th>Cell content</th>
<th>Field size</th>
<th>Mandatory</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Program</td>
<td>prog</td>
<td>The identifier for the Family and Carer Mental Health Program.</td>
<td>Code set:5 FCMHP</td>
<td>Char (1)</td>
<td>Y</td>
</tr>
</tbody>
</table>
| 2       | Team code                          | team         | A unique code for the individual team or agency providing services. A team may be 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 date of the reporting year and quarter.                                                                                                                                                           | year quarter  
Example: 20170331 | ‘yyyyymmdd’ Char (8) | Y         |
| 4       | Carer code -Provider               | car-code     | Provider carer code is unique 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 a code consisting of the second, third and fifth characters of a person’s family name, the second and third letters of the person’s given name, the day, month and year when the person was born and the sex of the person, concatenated in that order.  
NOTE: SLK should be used 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 | ‘XXXXXDDMMYYYY’ Char (14) | Y         |
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<tr>
<th>Itemno.</th>
<th>Data item</th>
<th>Field header</th>
<th>Metadata definition</th>
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</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>Carer Statistical Linkage Key (SLK)</td>
<td>slk</td>
<td>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 a code consisting of the second, third and fifth characters of a person’s family name, the second and third letters of the person’s given name, the day, month and year when the person was born and the sex of the person, concatenated in that order. NOTE: SLK should be used in Carer Star.</td>
<td>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.</td>
<td>‘XXXXXXDDMMYYYYN’ Char (14)</td>
<td>Y</td>
</tr>
<tr>
<td>6</td>
<td>Date of Birth</td>
<td>dob</td>
<td>The date of birth of the carer. The day, month and year when the person being provided services was born.</td>
<td>Year month day</td>
<td>‘yyyyymmd’ Char (8)</td>
<td>Y</td>
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<td>Itemno.</td>
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<tr>
<td>7</td>
<td>Date of Birth Status</td>
<td>dob_stat</td>
<td>An indication of whether any component of the person’s Date of Birth was estimated.</td>
<td>Code set: 1 Estimated 2 Not Estimated</td>
<td>Char (1)</td>
<td>Y</td>
</tr>
<tr>
<td>8</td>
<td>Sex</td>
<td>sex</td>
<td>The biological distinction between male and female, as represented by a code.</td>
<td>Code set: 1 Male 2 Female 9 Not stated</td>
<td>Char (1)</td>
<td>Y</td>
</tr>
<tr>
<td>9</td>
<td>LGBTQIA</td>
<td>LGBTQIA</td>
<td>Carer who identify as lesbian, gay, bisexual, transgender, queer or questioning, intersex and asexual or allied.</td>
<td>Y Yes N No U Unknown/ Not stated</td>
<td>Char (1)</td>
<td>Y</td>
</tr>
<tr>
<td>10</td>
<td>Aboriginal and Torres Strait Islander Origin (ATSI)</td>
<td>atsi</td>
<td>Whether a person identifies as being of Aboriginal or Torres Strait Islander origin, as represented by a code.</td>
<td>Code set: 1 Aboriginal but not Torres Strait Islander origin 2 Torres Strait Islander but not Aboriginal origin 3 Both Aboriginal and Torres Strait Islander origin 4 Neither Aboriginal nor Torres Strait Islander origin 9 Not stated</td>
<td>Char (1)</td>
<td>Y</td>
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<tr>
<td>11</td>
<td>Country of birth</td>
<td>cob</td>
<td>The country in which the carer was born, as represented by a code.</td>
<td>Numeric 4-digit ABS code from the ABS Standard Australian Classification of Countries, (ABS cat. no. 1269.0, SAC2016).</td>
<td>Char (4)</td>
<td>Y</td>
</tr>
<tr>
<td>12</td>
<td>Preferred Language</td>
<td>lang</td>
<td>The language most preferred by the carer for communication, as represented by a code.</td>
<td>A numeric 4-digit ABS code using the ABS Australian Standard Classification of Languages (ABS cat. no. 1267.0, ASCL 2016).</td>
<td>Char (4)</td>
<td>Y</td>
</tr>
<tr>
<td>13</td>
<td>Interpreter required</td>
<td>int</td>
<td>Whether an interpreter is required by the carer.</td>
<td>Y or N</td>
<td>Char (1)</td>
<td>Y</td>
</tr>
<tr>
<td>14</td>
<td>Suburb/town of residence</td>
<td>suburb</td>
<td>The name of the geographical district, town or suburb where the carer usually resides.</td>
<td>Example: Liverpool</td>
<td>Char (50)</td>
<td>Y</td>
</tr>
<tr>
<td>15</td>
<td>Postcode of residence</td>
<td>pcode</td>
<td>The postcode of the carer’s usual place of residence, provided by</td>
<td>Example: 2640</td>
<td>Char (4)</td>
<td>Y</td>
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<td>Itemno.</td>
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<td>Australia Post. Postcodes for post office boxes or other administrative centres should not be used.</td>
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<tr>
<td>16</td>
<td>Start date in Program with current CMO</td>
<td>start_date</td>
<td>The date the carer started in the current program with the current CMO</td>
<td>year month day</td>
<td>‘yyyyymmdd’ Char (8)</td>
<td>Y</td>
</tr>
<tr>
<td>17</td>
<td>Source of Referral</td>
<td>refer_src</td>
<td>Code set: 1 Self 2 Family or Friend 3 Public Mental Health 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</td>
<td>Char (2)</td>
<td></td>
<td>Y</td>
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<tr>
<td>18</td>
<td>Source of Referral (other)</td>
<td>refer_src_oth</td>
<td>Example: Corrective Services</td>
<td>Char (200)</td>
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</table>

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.

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<thead>
<tr>
<th>Itemno.</th>
<th>Data item</th>
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<tr>
<td>25</td>
<td>Number of minutes of individual carer support in 1. Information</td>
<td>infoind_mins</td>
<td>Individual support: General correspondence, phone conversation for information requests etc.</td>
<td>Equivalent to 15 minutes</td>
<td>‘NNNN’ Char (4)</td>
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<tr>
<td>26</td>
<td>Number of minutes of individual carer support in 2. Advocacy</td>
<td>adv_mins</td>
<td>Individual support: Advocacy provided on behalf of a single individual.</td>
<td>Equivalent to 30 minutes</td>
<td>‘NNNN’ Char (4)</td>
<td>Y</td>
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<tr>
<td>27</td>
<td>Number of minutes of individual carer support in 3. Emotional</td>
<td>emo_mins</td>
<td>Individual support: Assist carers to build resilience, capacity and</td>
<td>Equivalent to 60 minutes</td>
<td>‘NNNN’ Char (4)</td>
<td>Y</td>
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<tr>
<td>Itemno.</td>
<td>Data item</td>
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<tr>
<td>28</td>
<td>Number of minutes of individual carer support in 4. Education and Training</td>
<td>eduind_mins</td>
<td>Individual support: Educate or facilitate carers to build knowledge and skills.</td>
<td>Example: 0120 is equivalent to 120 minutes</td>
<td>‘NNNN’</td>
<td>Y</td>
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<tr>
<td>29</td>
<td>Number of minutes of individual carer support in 5. Referrals</td>
<td>ref_mins</td>
<td>Individual support: Refer carer to another service for further action.</td>
<td>Example: 0120 is equivalent to 120 minutes</td>
<td>‘NNNN’</td>
<td>Y</td>
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<tr>
<td>30</td>
<td>Number of minutes of individual carer support in 6. Travel</td>
<td>travelca_mins</td>
<td>Individual support: Travel – Time used to travel with carer.</td>
<td>Example: 0060 is equivalent to 60 minutes</td>
<td>‘NNNN’</td>
<td>Y</td>
</tr>
<tr>
<td>31</td>
<td>Number of minutes of individual carer support in 7. Other</td>
<td>oth_mins</td>
<td>Individual support: Support that does not fit into other categories.</td>
<td>Example: 0060 is equivalent to 60 minutes</td>
<td>‘NNNN’</td>
<td>Y</td>
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<tr>
<td>32</td>
<td>Description of individual carer support – 8. Other - specify</td>
<td>other_specify</td>
<td>Individual support: A description of the other one on one individual carer support that does not fit into other categories.</td>
<td></td>
<td>Char (200)</td>
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<td>37</td>
<td>Number of minutes of group activity in 9. Information</td>
<td>infogrp_mins</td>
<td>Group support: Information session.</td>
<td>Example: 0120 is equivalent to 120 minutes</td>
<td>‘NNNN’</td>
<td>Y</td>
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<tr>
<td>38</td>
<td>Number of minutes of group activity in 10. Education and Training</td>
<td>edugrp_mins</td>
<td>Group support: Educate or facilitate carers in a group setting to build knowledge and skills.</td>
<td>Example: 0060 is equivalent to 60 minutes</td>
<td>‘NNNN’</td>
<td>Y</td>
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<tr>
<td>39</td>
<td>Number of minutes of group activity in 11. Support group</td>
<td>supp_mins</td>
<td>Group support: Support group.</td>
<td>Example: 0060 is equivalent to 60 minutes</td>
<td>‘NNNN’</td>
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<tr>
<td>44</td>
<td>Number of minutes of indirect carer activity 12. Program administration</td>
<td>admin_mins</td>
<td>Number of minutes of support in carer administration (e.g. Making a booking or spending time to go through service options).</td>
<td>Example: 0120 is equivalent to 120 minutes</td>
<td>‘NNNN’</td>
<td>Y</td>
</tr>
<tr>
<td>45</td>
<td>Number of minutes taken to travel to and from carer</td>
<td>travelst_mins</td>
<td>Travel - Time used to travel to and from carer.</td>
<td>Example: 0030 is equivalent to 30 minutes</td>
<td>NNNN’ Char (4)</td>
<td>Y</td>
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<tr>
<td>Itemno.</td>
<td>Data item</td>
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<td>46</td>
<td>Other services - Community Services</td>
<td>ref_cs</td>
<td>Did the carer visit a community service (such as a women’s health centre or a Community Health centre) during this period?</td>
<td>Y or N</td>
<td>Char (1)</td>
<td>Y</td>
</tr>
<tr>
<td>47</td>
<td>Referrals to other services – Other</td>
<td>ref_other</td>
<td>Was the carer referred to other services during this period?</td>
<td>Y or N</td>
<td>Char (1)</td>
<td>Y</td>
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<tr>
<td>48</td>
<td>Referrals to other services – Other - specify</td>
<td>ref_other_spec</td>
<td>A description of the other services to which the carer have been referred during the period.</td>
<td>Example: Undefined NGO support services</td>
<td>Char (200)</td>
<td>Mandatory if Y reported at item 47.</td>
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List items 49 - 56 are the summary scores generated from the Carer Star outcome measure.

<table>
<thead>
<tr>
<th>Itemno.</th>
<th>Data item</th>
<th>Field header</th>
<th>Metadata definition</th>
<th>Cell content</th>
<th>Field size</th>
<th>Mandatory</th>
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<tr>
<td>49</td>
<td>Carer Star Chart completed</td>
<td>cs</td>
<td>Record whether a Carer Star measure has been completed during the quarter/period. It is expected that a Carer Star will be completed every quarter.</td>
<td>Y or N</td>
<td>Char (1)</td>
<td>Y</td>
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<td>50</td>
<td>Reason for Carer Star not completed</td>
<td>cs_n</td>
<td>A description of why Carer Star was not completed.</td>
<td>Example: unregistered carer, carer refused</td>
<td>Char (200)</td>
<td>Mandatory if N reported at item 49</td>
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<tr>
<td>51</td>
<td>Carer star - Health</td>
<td>cs_h</td>
<td>Managing physical and mental health; healthy lifestyle; doctors and other health services.</td>
<td>Code set: 1 Cause for concern 2 Getting help 3 No pressing concerns 4 Mostly OK 5 As good as it can be</td>
<td>Char (1)</td>
<td>Mandatory if Y reported at item 49</td>
</tr>
<tr>
<td>52</td>
<td>Carer Star - The Caring Role</td>
<td>cs_tcr</td>
<td>Skills; understanding; practical caring; legal issues; planning ahead; communicating with professionals.</td>
<td>Code set: 1 Cause for concern 2 Getting help 3 No pressing concerns 4 Mostly OK 5 As good as it can be</td>
<td>Char (1)</td>
<td>Mandatory if Y reported at item 49</td>
</tr>
<tr>
<td>53</td>
<td>Carer Star - Managing at home</td>
<td>cs_mah</td>
<td>Day-to-day tasks and the suitability of your home – or that of the person you care for if you don’t live with them.</td>
<td>Code set: 1 Cause for concern 2 Getting help 3 No pressing concerns 4 Mostly OK</td>
<td>Char (1)</td>
<td>Mandatory if Y reported at item 49</td>
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<tr>
<td>Itemno.</td>
<td>Data item</td>
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<td>Metadata definition</td>
<td>Cell content</td>
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<td>54</td>
<td>Carer Star - Time for yourself</td>
<td>cs_tfy</td>
<td>Social life; activities; breaks from hands-on caring.</td>
<td>5 As good as it can be</td>
<td>Char (1)</td>
<td>Mandatory if Y reported at item 49</td>
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<tr>
<td>55</td>
<td>Carer Star - How you feel</td>
<td>cs_hyf</td>
<td>Feeling supported; dealing with anxiety or stress; managing any difficulties in a key relationship.</td>
<td>5 As good as it can be</td>
<td>Char (1)</td>
<td>Mandatory if Y reported at item 49</td>
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<tr>
<td>56</td>
<td>Carer Star - Finances</td>
<td>cs_f</td>
<td>Benefits; debts; managing money; legal issues.</td>
<td>5 As good as it can be</td>
<td>Char (1)</td>
<td>Mandatory if Y reported at item 49</td>
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<tr>
<td>57</td>
<td>Carer Star - Work</td>
<td>cs_w</td>
<td>Matters related to paid work; support or welfare within paid work; desire to return to paid work</td>
<td>5 As good as it can be</td>
<td>Char (1)</td>
<td>Mandatory if Y reported at item 49</td>
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</table>
### 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)**

   - Far West
   - Western
   - Northern Syd 12
   - SW Sydney
   - Nepean BM
   - Murrumbidgee
   - Illawarra SH
   - Hunter NE
   - SE Sydney
   - Western Sydney
   - North Coast
   - Northern NSW

5. **Date form was completed**

   - day
   - Month
   - Year

6. **Date of birth**

   - day
   - Month
   - Year

7. **Sex (tick one)**

   - Female
   - Male
   - Unknown/other

8. **Main language spoken at home (tick one)**

   - English
   - Other

9. **How did the client find out about your service (tick one)**

   - Family/friend
   - Brochure/flyer
   - Advertisement
   - Acute mental health service/hospital
   - Community mental health
   - Private psychiatrist
   - GP
   - Other government service
   - Other NGO
   - Other, specify:

10. **Indigenous status**

   - Aboriginal
   - Torres Strait Islander
   - Neither
   - Not known

11. **Special needs group (tick one for each, do not leave any blank)**

   - CALD
   - Physical or sensory impairment
   - Geographical isolation

12. **How long in caring role (tick one)**

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

13. **Government pension/benefit (tick all that apply)**

   - Carer allowance
   - Carer payment
   - Other pension/benefit
   - No government pension/benefit

14. **Employment status (tick one)**

   - Full-time
   - Part-time
   - Unemployed
   - Retired or not in labour force
   - Casual

15. **Initial client needs (tick all that apply)**

   - Information
   - Emotional support
   - Education and training
   - Advocacy
   - 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 is to 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
   - [ ] 1 Schizophrenia
   - [ ] 2 Bipolar disorder
   - [ ] 3 Schizo-affective
   - [ ] 4 Personality disorder
   - [ ] 5 Depression
   - [ ] 6 Anxiety
   - [ ] 7 Undiagnosed/unknown
   - [ ] 8 Other, specify: __________________________
   - Secondary
   - [ ] 1 Schizophrenia
   - [ ] 2 Bipolar disorder
   - [ ] 3 Schizo-affective
   - [ ] 4 Personality disorder
   - [ ] 5 Depression
   - [ ] 6 Anxiety
   - [ ] 7 Undiagnosed/unknown
   - [ ] 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 in last 6 months?
   - [ ] 1 Yes
   - [ ] 2 No
   - [ ] 3 Not known

24. Is the consumer’s mental health managed by a primary care health professional or a private 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 is to 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 primary and all secondary that apply)
   - Primary
   - [ ] 1 Schizophrenia
   - [ ] 2 Bipolar disorder
   - [ ] 3 Schizo-affective
   - [ ] 4 Personality disorder
   - [ ] 5 Depression
   - [ ] 6 Anxiety
   - [ ] 7 Undiagnosed/unknown
   - [ ] 8 Other, specify: __________________________
   - Secondary
   - [ ] 1 Schizophrenia
   - [ ] 2 Bipolar disorder
   - [ ] 3 Schizo-affective
   - [ ] 4 Personality disorder
   - [ ] 5 Depression
   - [ ] 6 Anxiety
   - [ ] 7 Undiagnosed/unknown
   - [ ] 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 in last 6 months?
   - [ ] 1 Yes
   - [ ] 2 No
   - [ ] 3 Not known

32. Is the consumer’s mental health managed by a primary care health professional or a private health professional?
   - [ ] 1 Yes
   - [ ] 2 No
   - [ ] 3 Not known
Appendix 3  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 4  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 5  
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?