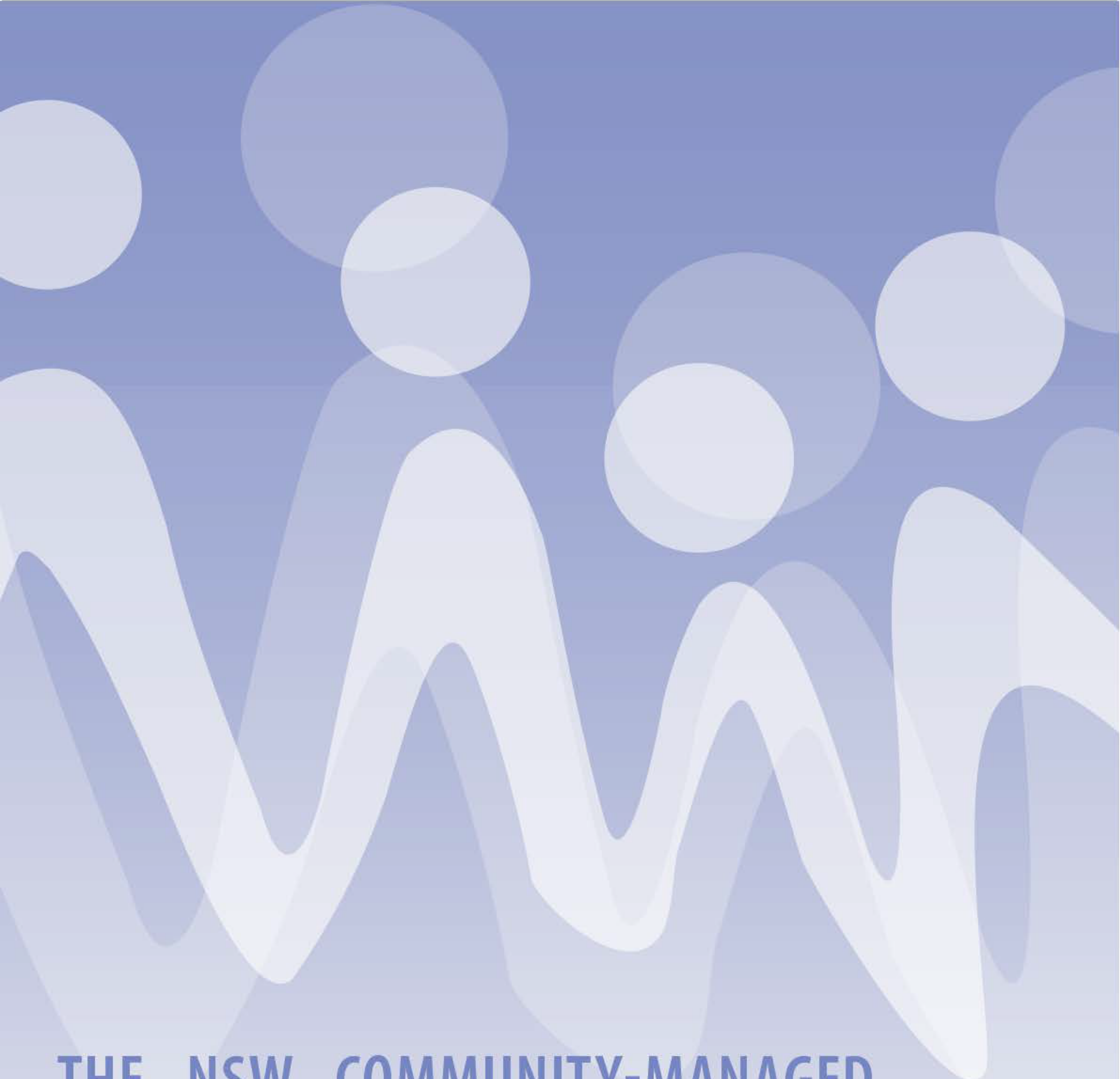


THE NSW COMMUNITY-MANAGED MENTAL HEALTH SECTOR

DATA MANAGEMENT STRATEGY REPORT

mhcc
Mental Health
Coordinating Council

PHASE ONE
October 2010

mhcc
Mental Health
Coordinating Council

THE NSW COMMUNITY-MANAGED MENTAL HEALTH SECTOR

DATA MANAGEMENT STRATEGY REPORT: PHASE ONE

October 2010

For referencing purposes please use the following protocol:

Mental Health Coordinating Council. (2010). The NSW Community-Managed Mental Health Sector Data Management Strategy Report: Phase One. NSW Australia

Authors: Millard, Julie & Bateman, Jenna, (2010). MHCC NSW Australia

Mental Health Coordinating Council
PO Box 668 Rozelle NSW 2039

Acknowledgements

MHCC acknowledges and appreciates the contribution of many people to the Data Management Strategy and in the preparation of this report.

- NSW Health for funding the Data Management Strategy Project
- Data Management Strategy Reference Group Members
- Members of the MDS, Systems and Data Dictionary Working Groups
- Consultants to MHCC – Jonine Penrose-Wall and Tully Rosen
- Other individuals who provided advice, suggestions, assistance at critical times and feedback on this report.

About the Mental Health Coordinating Council of NSW (MHCC)

The Mental Health Coordinating Council (MHCC) is the peak body for community-managed organisations (CMOs) working for mental health throughout New South Wales. MHCC provides leadership and representation on mental health issues, improving the NSW community's mental health by developing CMOs to provide high quality services.

The Mental Health Coordinating Council (MHCC):
- Is an independent voice on mental health issues for members such as service providers and consumer & carer organisations
- Facilitates links between Government, CMOs, and private agencies, in the role of a liaison body
- Provides leadership for sector capacity building.

Funded by NSW Health

Table of Contents

Appendices

Introduction

In our current environment of rapidly changing technology in which there is an increasing need to demonstrate accountability to consumers and funders, and pressure to use data more effectively, many community-managed organisations are looking to enhance their capacity to produce comprehensive data that reports activity and meaningful outcome data. Community-managed organisations understand the link between access to high quality data and organisational quality improvement, with the need for enhanced data to inform research into the effectiveness of programs delivered by the community sector, and to provide identification of unmet need and future growth areas.

The major achievements of this project are development of data sets, both comprehensive and minimum for application by the broad mental health community-managed sector. The data sets are consumer-focused, recognise the role of carers, have rationales for inclusion of data elements and are compatible with the national data dictionaries. In addition, the project has established a set of criteria against which organisations can assess the applicability of data systems to their specific requirements including links to human resource and occupational health and safety processes.

These are significant outcomes achieved through the dedicated engagement of industry representatives from a range of organisations working in the mental health sector.

It has to be acknowledged, however, that these achievements are only a first step or initial phase towards establishment of a comprehensive data management strategy for the community-managed mental health sector. Ensuring organisations have adequate data systems to employ standardised data sets is an obvious starting point and this is a substantial component of the planned Phase 2 of this strategy outlined within this report. Other considerations are examination of how standardised data sets apply to different program and organisational types; how consumer privacy is maintained, and how data collection and management training is provided to ensure data security, validity and consistency.

There are also the larger questions for mental health community organisations in relation to the collection and collation of standardised program data: where and with whom should this data be stored; who should have access to it and at what level should access be granted. Currently in the NSW mental health sector, data is held by the funding provider only, however some sectors have established roles for external bodies in collection and monitoring of organisational data, e.g. the peak bodies for women’s health organisations and for drug and alcohol residential services both undertake data collection and monitoring roles.

At the national level, the different data requirements of the state and federal funding departments being reduced to one agreed data set for community-managed organisations is a major ambition.

The Australian Institute of Health and Welfare has this year reviewed the data use and needs of NGOs in each jurisdiction. The National Mental Health Information Subcommittee, of which the alliance of state mental health peaks Community Mental Health Australia is a member, has commenced addressing this work. The Data

Management Strategy project has already contributed substantially to the aims of these national priorities.

I commend this report to any organisation exploring how to achieve better data collection, management and use. Special thanks to all the industry representatives who assisted in the detailed and exacting process of the project’s development.

Best wishes

Jenna Bateman
CEO Mental Health Coordinating Council

1. Executive Summary

Without effective data management systems the gains made over the last several years in quality processes, uptake of consumer outcome monitoring and workforce development will fail to have an optimum impact on service delivery in NSW.

Every service provided by a community-managed organisation (CMO) is different. Data collected can enhance the support of consumers and carers, assist with program development, planning and growth, and help to identify any unmet needs for the CMO sector. Data can be so much more than just a minimum data set sent to funding bodies.

The information management needs of the CMO sector are changing dramatically. An increasing number of CMOs now have contractual agreements with both Commonwealth and State government departments. CMOs report separately to each of the funding bodies on different aspects of their work. There is no overarching mechanism by which to understand the service delivery characteristics and outcomes of CMO mental health programs or the total impact of the sector.

The development of an evidence-based, recovery-oriented CMO service system that enhances knowledge creation and management, improves relationships with consumers and carers and builds on quality performance systems is the focus of the MHCC Data Management Strategy.

Through the work of the CMO members on the Reference Group and the three working groups i.e. 1) MDS; 2) Systems and 3) Data Dictionary; NSW CMOs working in mental health are a step closer towards being able to access and understand CMO data.

Issues that impact on the effectiveness of the quality of services being delivered include CMOs having little or no IT infrastructure for data collection; data collected may not be sufficiently meaningful for the organisation nor have benefits for consumers, and an inability to use data collected for other valuable purposes. For example, having the capacity to use data for research projects, exchange data with other CMOs to monitor partnership progress on joint projects, or capturing critical incident management and monitoring processes.

2. Recommendations

The following recommendations have arisen from the findings in this report, and are proposed as a way forward to promote best practice data management systems, improve service provision and for CMOs working in mental health in NSW. It is recommended that:

1. MHCC work with NSW Health and other funding agencies to reach agreement on a core Minimum Data Set, and the collection and use of CMO data.

2. MHCC commence discussions with government agencies to seek cross-government collaboration about the content and process of CMO reporting by state and federal governments.

3. MHCC commence Phase 2 of the Data Management Strategy, including a scoping study to determine the technology infrastructure requirements of CMOs working in mental health in NSW, and development of a business plan to enhance CMOs' technology capacity.

4. MHCC Learning and Development Unit undertake (i) training of CMO staff in the use of data sets and data systems (ii) integration of outcome measurement education across all relevant CMO training packages and (iii) develop an Outcome Measurement User Manual for CMOs working in mental health in NSW.

5. MHCC investigate corporate licensing options to enable access to a cost-effective data management system for small and medium mental health CMOs.

6. MHCC, the CMO sector, NSW Health and other government agencies commence discussions with regard to development of a mechanism whereby CMO data can be accessed by a range of stakeholders including CMOs, peak bodies, government agencies and research institutes based on a level of authority access structure. This would enable collection of de-identified sector data for quality improvement, benchmarking, and research purposes.

7. MHCC commence discussions with Community Mental Health Australia regarding the establishment of a national mental health CMO clearinghouse. This organisation would collect best practice from mental health CMOs, which would be publicly available to consumers, carers, MHCC members, the sector and funding bodies.

3. Background

Without definitions there can be no measurement;
without measurement there can be no data;
without data there can be no monitoring;
and without monitoring there can be no evidence-based policy, effective advocacy, or public accountability.[1]

3.1 Purpose and Objectives

The growth in technology over the past few decades has transformed every aspect of life, and it is an ongoing challenge to keep up-to-date with developments in the application of technology. In the human services sector, the requirements of funders for routine organisational and program performance information increases the pressure on Community-Managed Organisations (CMOs – also known as Not-For-Profit and Non-Government Organisations) to improve data management systems. Governments and CMOs are facing complex decisions about the nature and use of electronic data and information management systems. CMOs are information rich, yet data poor.

The purpose of MHCC's Data Management Strategy is to explore how CMOs working in mental health in New South Wales (NSW) can apply technology to make optimal use of the information gained through program delivery thereby improving outcomes for individuals.

The objectives of this project are to:

- Develop an agreed Comprehensive Data Set and proposed Minimum Data Set for CMOs working in mental health in NSW.
- Identify the current status of government activities data management systems.
- Collate information about best practice in data systems relevant to mental health CMOs, by referring to international and Australian research and practices.
- Identify specific data management systems that can enable mental health CMOs to make effective and efficient use of information.
- Recommend the way forward for CMOs working in mental health and their funders to improve data systems, and thereby the quality of services for consumers and accountability to funders.

---

[1] UNICEF 2008

3.2 Context

This project focuses on mental health CMOs operating in NSW, and occurs in the context of several significant activities, including:

- Quickly changing technological capabilities
- Increasing requirements on organisations to demonstrate accountability to consumers and funders
- A range of commonwealth and state government activities to build the data management capacity of the mental health sector
- Need of CMOs to use data more effectively in ways that are administratively efficient and effective.

Note: The use of the words ‘Consumer’ and ‘Client’ in this report have the same meaning and are recorded directly from documents.

3.3 Principles

1. MH CMOs are recognised as a core component of the mental health service system.

2. Understanding the contribution of the CMO MH sector and establishing a clear evidence base for its activities underpins the further development of the sector.

3. The CMO MH Data Management Strategy targets services funded under dedicated mental health funding streams at both state and federal levels.

4. In this environment of rapidly changing technology CMOs and Government agencies recognise the opportunity for improvement in IT infrastructure, data collection and usage across the MH CMO sector.

5. The Mental Health CMO sector requires access to demographic and outcomes data to enable quality improvement, benchmarking and population needs based planning.

6. That MHCC agencies and all funders should work towards a common set of data specifications, ensuring that data items have a consistent and shared definition throughout the sector and do not differ between agencies or funding programs/

7. That MH CMOs and funding agencies should work together to minimize data collection burden on MH CMOs by trying to find the smallest set of data items which meets the needs of as many funders as possible

8. That MH CMOs and funding agencies should establish agreement to minimize additional data collection requirements (e.g. for specialty programs) over and above an agreed core dataset, and to ensure that these are developed in consultation and negotiation with the sector.

9. That data specification and collection requirements and information systems need to remain flexible to account for ongoing developments in policy priorities, funding and service organization.

4. Role of Community-Managed Organisations

Community-Managed Organisations (CMOs) provide a broad range of services and programs for community members with a common need or interest. Other terms used for CMOs include non-government organisations (NGOs), Not-for-Profit, and the Third Sector.

Mental health CMOs complement the work of government and private health services to support people experiencing mental illness and/or mental health problems and are essential to the mental health system as a whole.

CMOs:

- Are flexible and responsive to changes in consumers' needs and able to incorporate changes in social policy
- Encourage consumer and carer empowerment and participation
- Work to optimize an individual's capacity to lead a meaningful and purposeful life.
- Innovate and create new programs and services to meet identified need
- Undertake research, and
- Build social capital.

The valuable contribution of the mental health CMO sector in improving the wellbeing of the people of NSW is slowly gaining long overdue recognition. As the immense benefits of the CMO sector are being realised governments are devoting considerable resources to ensure CMOs continue in their essential roles.

NSW: A New Direction for Mental Health[2] provides guiding principles on the role of NSW Health and the Community-Managed Mental Health sector in providing programs for people requiring mental health support. To support these goals this document proposes that the Community-Managed Mental Health Sector work with funding agencies to develop and agree on explicit expectations, particularly in the collection and use of data and developing the CMO sector in order to provide effective support.

The recommendations by MHCC throughout this report propose the way forward for funding bodies and mental health CMOs to improve data collection and use and thereby the quality of services for consumers and accountability to funders.

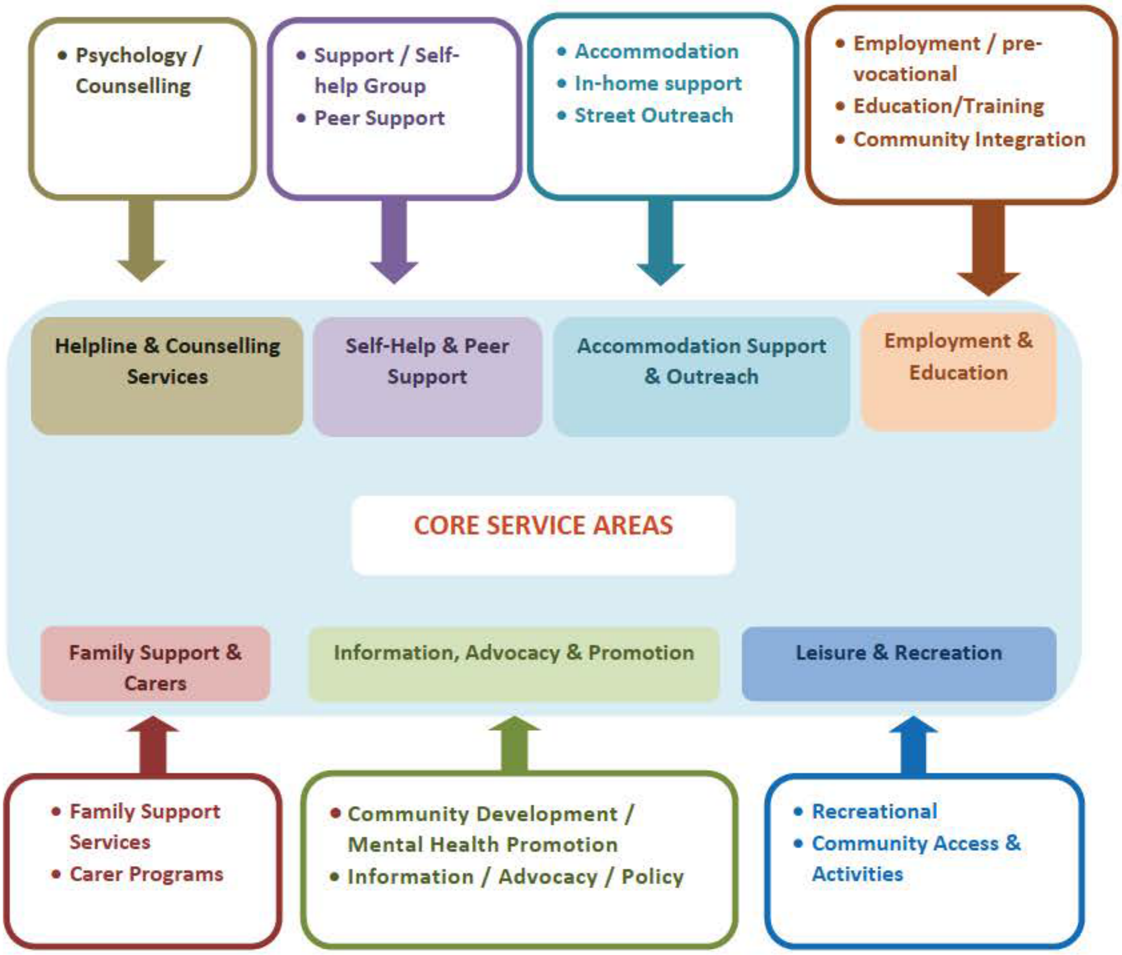
Mental health CMOs are funded from a range of state and federal government and other sources, and provide a diverse range of services.

CMOs are categorized into seven core service areas as shown in Figure 1.

---

[2] NSW Health 2006

Figure 1 **Categorisation of Program Types into Core Services**



CMOs want the capacity to use data for their own organisational, and sector research projects[3]

---

[3] Statement of Data Management Strategy Reference Group member, 2009

5. Data Management Strategy

This report describes the findings of Phase 1 of the Data Management Strategy undertaken from February 2009 to May 2010. NSW Health funded the DMS project as part of the Infrastructure Grants Program, as described above.

The reason for the DMS project as stated by Jenna Bateman, MHCC Chief Executive Officer (CEO) is:

> ***"Poor information technology infrastructure and a coherent data system for NGOs is the single most limiting factor to the continued capacity of the sector to provide efficient evidence-based programs to mental health consumers and carers.***
> ***Without effective data management systems the gains made over the last several years in quality processes, uptake of consumer outcome monitoring and workforce development will fail to have an optimum impact on service delivery."***[4]

The development of an evidence-based, recovery-oriented CMO service system that enhances knowledge creation and management, improves relationships with consumers and carers and builds on quality performance systems is the focus of the MHCC Data Management Strategy.

5.1 Project Methodology and Findings

The project methodology was developed within the guiding principle that the development of data management systems be consumer and carer-focused and responsive to CMOs working in mental health and the agencies that provide funding.

The key components of the project were as follows:

- Project planning
- Establishing a project Reference Group
- Convening three working groups, each with a specific task.
    1. Minimum Data Set - Develop a proposed Minimum Data Set (MDS) for NSW CMOs working in mental health
    2. Systems – Review and recommend database system/s that are affordable, innovative, accessible and flexible for both large and small CMOs
    3. Data Dictionary - Produce a user-friendly Mental Health CMO MDS Data Manual.

---

[4] Bateman, J., *Background Paper for Data Management Systems,* Mental Health Coordinating Council 2009

- Attendance at meetings with NSW Health, NADA, CEOs of mental health CMOs
- Promotion of the project at the MHCC/ NADA Conference 2009
- Use of data from MHCC Sector Mapping Project
- Engagement with Australian Institute of Health and Welfare and the National Mental Health Information Strategy Sub-Committee
- Compliance with National Health and Community Services Data Dictionaries, where possible
- Literature search on best practice in information technology, data use in the community sector internationally, and existing data systems.

There is currently no national comprehensive data management system for CMOs working in mental health. One task of this project was to review and identify such a system, which would be compatible with other relevant systems, and be based on best practice principles and expertise developed to date. Another key task of this project was to identify issues affecting the implementation of the proposed new data management system.

The following information is an outline of the methodology used to deliver Phase 1 of the MHCC Data Management Strategy.

Aims

The key aims of the Data Management Strategy were to:

- Ensure consumer-focused, sector-driven approach
- Develop a Comprehensive Data Set and proposed Minimum Data Set (MDS) for NSW CMOs working in mental health
- Recommend database systems that are affordable, innovative, accessible and flexible for both large and small CMOs
- Produce a Mental Health CMO MDS Data Dictionary that is user-friendly.

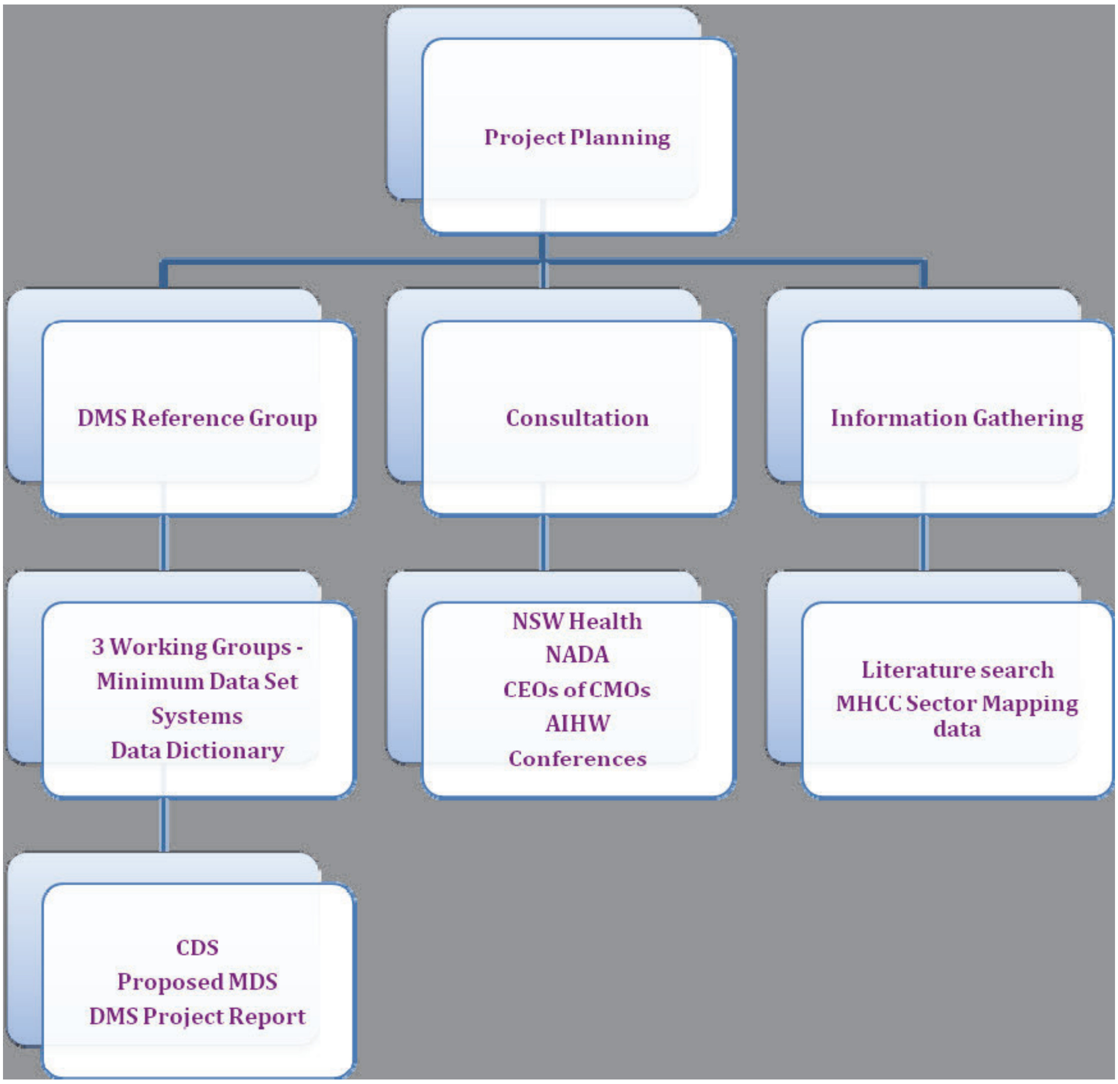
Key Activities

To achieve the aims, this project involved 15 key activities, as follows:

1. Engage a consultant part-time to manage and coordinate the Data Management Strategy for CMOs working in mental health in NSW
2. Undertake initial information review of available literature e.g. previous project reports, government frameworks to inform project's development
3. Develop a Project Background paper for MHCC members and key stakeholders to inform mental health CMOs and key stakeholders of the project and to contextualise the project
4. Establish and maintain Data Management Strategy (DMS) Reference Group
5. Establish and maintain Minimum Data Set (MDS) Working Group
6. Establish and maintain Systems Working Group
7. Consult with the Project Manager and acquire data from MHCC Mapping Sector Survey
8. Participate in the Mental Health and Drug and Alcohol Information Sub-Committee and NGO Sub-Committee
9. Become a member of NADA NGO Drug & Alcohol and Mental Health Information Management Project Advisory Group
10. Consult with CMO sector regarding data collection and use
11. Disseminate information and promote DMS Project at CEO Forum and conferences
12. Report Monthly MHCC Board Meeting Reports and quarterly IGP Reports and to CEO
13. Establish and maintain Data Dictionary Working Group (redirection Dec 2009 – see Section 5.1.3)
14. Identify MDS requirements for Federal and State funding sources – 20+ sources
15. Formulate Data Management Strategy Report with recommendations

Additional information about the methodology for this project is at Appendix E.

Diagram of Process



The MHCC Data Management Strategy Project commenced in late February 2009. A DMS Reference Group and three working groups were established and maintained by the DMS Coordinator.

CMO representatives were invited to contribute to the development of key components of a new data management system for mental health CMOs. The working groups communicated closely with each other to ensure consistency in approach and that outcomes would be compatible. The majority of the groups completed their objectives, identified issues affecting implementation, and made recommendations to promote ongoing improvement for the data needs of the CMO sector working in mental health.

A full list of members of the DMS Reference Group and the three Working Groups' are at Appendices A, B and C.

5.1.1 DMS Reference Group

The DMS Reference Group met quarterly on 6 occasions and provided advice, guidance and assistance to the project. All MHCC members were invited to participate, as all have an interest in the outcomes of the project. The Reference Group's role was to:

- Ensure MHCC Data Management Strategy meets the needs of the NSW CMO sector.
- Ensure the Data Management Strategy aligns with relevant federal and state data requirements and data collection.
- Assist the Strategy by providing a forum for discussion, problem-solving and brainstorming.
- Provide comment on reports and other material generated through the Data Management Strategy.
- Provide advice and information on technical requirements for implementing the Strategy.
- Provide advice and assistance in developing initiatives &/or resources when required and able
- Promote the Data Management Strategy to the CMO sector where able and appropriate.

Twenty-four individuals from sixteen CMOs, peak body and a government department attended the inaugural DMS Reference Group on 30 March 2009. A DMS Briefing paper and draft Terms of Reference for the Reference Group were tabled with discussion on the need for a review of data management for NSW CMOs, in collaboration between the NSW mental health and drug and alcohol sectors.

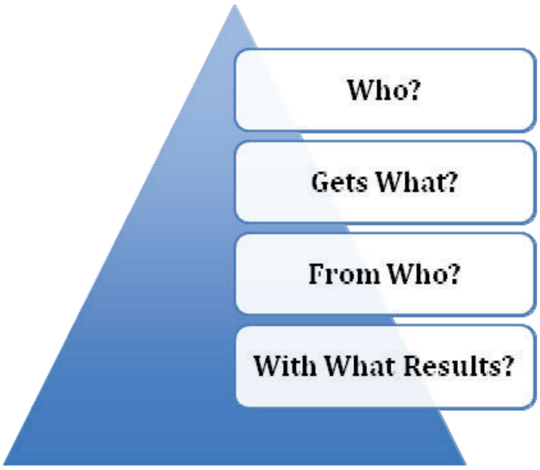
Discussion occurred on the developments in NGO data management in Victoria and Western Australia, the draft data dictionary, and preliminary data from the MHCC Sector Mapping Survey.

There was general discussion on the challenges for CMOs, i.e.:

- Limited funding to establish and maintain data systems.
- Staff training and IT support costs.
- Need to supplement routine data collection with research and development of brief interventions.
- Government to understand the diverse work of CMOs.
- Recognition that government values face-to-face service provision rather than the establishment and maintenance of partnerships and pathways for consumers.

It was agreed that:

- The peak body requires state-wide data to highlight gaps in service provision and make recommendations for inclusion in the State Budget.
- The CMO sector needs to have access to a data system that prioritises outcomes for consumers and carers; that provides data to service providers that assists in providing feedback to individual service users and to plan organizational directions and not only to provide reports to funders.
- A consistent data management system that assists CMOs and the sector without burden is required.
- The data management system needs to be flexible, able to meet diversified organisations' needs, user and cost-friendly, have back-up system and support, meet governments' minimum data set and funding requirements, and can be used by CMOs who have a wide variety of funding sources.
- Data collected by CMOs should be able to answer the following questions:



Members of the Reference Group were asked to consider active participation, or nomination of a representative, for one or more of the working groups.

Working Groups

The three working groups of the Data Management Strategy reflect the three key components of data management systems that are:

1. Minimum Data Set
2. Systems
3. Data Dictionary

5.1.2 Minimum Data Set Working Group

The Minimum Data Set (MDS) Working Group was consistent and enthusiastic in achieving its aim of developing a Comprehensive Data Set (CDS) for NSW CMOs working in mental health. Relevant features are:

- The CDS is consumer-focused, has a recovery-oriented approach with consideration of carers.
- Privacy and confidentiality are considered paramount.
- The CDS was developed by CMOs in consideration of content specific to meet individual, organisational and funders' needs.
- Tools, literature and approaches were to be culturally appropriate, where possible.
- Minimum data set of fields encapsulated according to funding requirements.
- Capacity to track changes in funding sources and service types.
- Capacity for CMOs to hide fields that are not relevant to their requirements.

The DMS Comprehensive Data Set has been developed to capture the data collection and funding requirements of diverse CMOs working in mental health in NSW, i.e. the seven program types:

1. Helpline and Counselling Services
2. Self-Help and Peer Support
3. Accommodation Support and Outreach
4. Employment and Education
5. Family Support and Carer Programs
6. Information, Advocacy and Promotion
7. Leisure and Recreation

The comments applied to each metadata item are designed to ensure that each definition is clear, concise, comprehensive and provides sufficient information to ensure that individuals who collect, provide, analyse and use the data are able to understand its meaning.

The MDS working group commenced in April 2009 and met for one year, with an initial contingent of 16 individuals representing 12 CMOs. The working group met on 20 occasions, including for one whole day with each member undertaking tasks outside of the meeting parameters.

The working group developed the CDS by undertaking the following tasks:

- Evaluation of existing data collection systems required by funding bodies.
- Identification of examples of current data systems in use by CMOs.

- Evaluation of CMOs' compliance with those systems, and any identified issues arising.
- Consultation with key stakeholders about draft data collection sets.
- Review of all relevant articles, reports, frameworks, legislation and guidelines.
- Development of the CDS in line with national data dictionaries' data elements, where possible with rationales provided for new or adapted items.
- Development of a data collection set that incorporates existing systems, and demonstrates best practice.

It is noted that the CDS may not include all possible data elements for CMOs working in mental health in NSW. However it is considered that CMOs and government agencies may request additional data fields to meet their organisational needs, or hide data fields that are not required by the service.

The following documents are available:

1. Comprehensive Data Set – Appendix G
2. Inclusion and Exclusion Rationales for the CDS – Appendix H
3. Proposed Minimum Data Set - Appendix I

During the development of the Comprehensive Data Set, several issues arose for review and consideration by the working group. These were:

- Compatibility
- Diverse funding sources and reporting requirements
- Areas of overlap and gaps
- Capacity of CMOs, and value of data collection

Compatibility

The group ensured that the Comprehensive Data Set was compatible with broad sector practices, with particular regard to the following areas:

- Differences between existing data sets for consumers and carers in NSW. The group addressed this issue by initially developing two data sets, one for each group. This ensured that differing terminology and emphasis could be maintained. The two data sets were combined to form the CDS.
- CMOs can elect to hide fields that are not relevant to their specific service profile.
- It was considered essential that the CDS was compatible (where possible) with the content and terminology used in the National Health and National Community Service Data Dictionaries. The work of the MDS group informed the Data Dictionary Working Group to ensure consistency.

- The group attempted to ensure that CDS data fields were compatible with the data systems used by NSW Health and other specific health funders.
- It was determined to use the ICD10-AM[5] rather than the DSM IV due to the increasing global use of the ICD10[6].

Diverse Funding Sources and Reporting Requirements

Collectively, NSW CMOs working in mental health provide reports to an extensive range of funders, primarily government bodies, each requiring different formats. Some data is similar for all funders and some data is exclusively required.

Therefore, the challenges for CMOs include:

- Ensuring their own data collection systems are consistent with relevant funders' requirements.
- Producing multiple reports, each with different but similar data sets.
- Managing the impact of duplication for administration time.

Program Funding

CMOs reported receiving mental health funding, apart from Area Health Service funding, from NSW Health through the NGO Grant Program, with:

- Responding CMOs reporting 61% of all programs are funded recurrently
- 39% of responding programs are funded by the NSW Government - across 4 government departments
- 29% of responding programs are funded by the Federal Government - across 3 government departments

Table 4 identifies examples of the known funding bodies and programs for CMOs in NSW, although there may be other sources and funded programs not included here.

---

[5] *International Classification of Disease, Revision 10 - Australian Modification*

[6] *Diagnostic and Statistical Manual for Mental Health Disorders, version 4*

Table 4: Examples of Funding Sources for CMOs

Funding Bodies	Program
Commonwealth Department of Health and Ageing (DoHA)	Children of Parents with a Mental Illness Initiative (COPMI) Community-Based Activities Program LIFE Framework Suicide Prevention Program National Carer Counselling Program National Suicide Prevention Strategy National Youth Mental Health Foundation - Headspace programs Support for Day to Day Living in the Community Program (D2DL) Telephone Counselling Self-Help and Support Programs
Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA)	Australian Disability Enterprises Mental Health Community-Based Programs Mental Health Respite Care Program Personal Helpers and Mentors Program (PHaMS)
Commonwealth Department of Education, Employment and Workplace Relations (DEEWR)	Disability Employment Services (DES) Job Placement, Employment and Training Program
Commonwealth Department of Immigration and Citizenship	Integrated Humanitarian Settlement Strategy
NSW Health	HIV-Related Programs Housing & Accommodation Support Initiative (HASI) Mental Health Family and Carer Support Services Program NGO Grant Funding Programs Recovery and Resource Services Program (RRSP)
NSW Department of Human Services	Area Assistance Scheme Home and Community Care Programs (HACC) NSW Parenting Program for Mental Health

Funding Bodies	Program
	Staying Home, Leaving Violence Program Supported Accommodation and Assistance Programs (SAAP)
NSW Community Relations Commission	Community Development Grants Program
NSW Department of Education and Learning	Links to Learning Program
NSW Department of Corrective Services	Community Funding Programs Victims of Violent Crimes Grants Program
Clubs NSW through Local Government	Community Development Support Expenditure Scheme (CDSE)
Philanthropic Trusts: Independently financed programs, such as corporate and private sponsorship - examples	Benevolent Society Danks Trust Mercy Foundation NIB Foundation Paul Newman Foundation Sony Foundation

Areas of Overlap and Gaps

The MDS Working Group compared the existing data collection sets, and found a set of fields that is a common requirement of all funders. This area of overlap is considered to be essential for all mental health CMOs, and forms the basis for the proposed Minimum Data Set for the sector.

There is also duplication of data collection between CMOs and mental health services, as evidenced by the quarterly collection of inpatient (planned and unplanned) admissions data by CMOs as a requirement of the NSW HASI program[7].

The group also found there were significant gaps, where specific data is either not being collected, or what is being collected is insufficiently comprehensive or not standardised across CMOs. As a consequence, important information is currently not available for monitoring, evaluation, and organisation/ sector growth planning.

---

[7] NSW Health, *HASI Monitoring Form 2: Clients Receiving Support*, MHDAO 2010, Version 5, p3

Examples of the key gaps identified that are included in the proposed CDS are:

- Fields to collect data on consumers' whole of life span.
- Information on carers, when the consumer is the client.
- Capacity to clearly identify individuals who are from an Aboriginal or Torres Strait Islander background, their nation and/or their grandparent's nation, such as currently occurs for people from cultural and linguistically diverse backgrounds.
- Data about consumers' comorbidity, which is currently collected by some programs e.g. HASI program, and not others.
- A data field to provide individuals who are transgender an opportunity to record their identity choice.
- Information about children of parents with a mental illness.
- Data about consumers' forensic history. The inclusion of this aspect has some complex issues, such as a potential breach of consumers' privacy, whether or not consumers should be asked (or required) to disclose this type of information, and the duty of care responsibilities of CMOs regarding worker safety. Current practice is varied, depending on the funding program requirements. The CDS includes fields that are at a level of probity comparable to persons applying for employment, involving their consent for criminal record checks to be undertaken.
- Service responsiveness and service satisfaction from the perspective of consumers and carers is missing, with an MH-COPES equivalent, for example the CEO-NGO (Consumer Evaluation of NGOs tool) or adaptation required to drive change in CMO services.

Outcome Measures

The CDS provides a snapshot of sector-wide outcome measures that are evidence-based, and examples of tools commonly used for assessment of consumer needs, monitoring and recovery processes and funding requirements. It is not clear how results of outcome measures are collated or used for broader evaluation in the sector. The majority of funding bodies do not provide regular data summary reports, showing how their data is used for program evaluation and future planning to CMOs or MHCC.

The working group found there was a lack of clarity around how CMOs captured information about consumers' social inclusion and community connectedness. The use of outcome measures is individually and organisationally determined to meet the identified service or community need, or funding requirements.

Some government funders set outcome measurement requirements for CMOs. For example the NSW Recovery and Resource Services Program (RRSP) require the completion of the APQ6, with the HASI program requiring CMOs to ensure the completion of the GAF and CANSAS outcome measures. The HASI Program previously required CMOs to complete the GAF, PWI and CANSAS while also collecting MH-OAT data, i.e. LSP-16, K10+LM, and HoNOS scores from area mental health services[8].

NSW CMOs now collect the GAF and the CANSAS, and include MH-OAT data from the Area Health Service. See Appendix M to identify Acronyms.

Measuring Process, Outcomes and Impact: Outcome Monitoring

The Sector Mapping Project participants were asked to indicate which of the following tools they used for monitoring outcomes:

- Health of the Nation Outcome Scales (HoNOS)
- Health of the Nation Outcome Scales for Children and Adolescents (HoNOSCA)
- Health of the Nation Outcome Scales 65+ (HoNOS65+)
- Life Skills Profile 16 (LSP-16)
- Kessler-10 Plus (K-10+)
- Camberwell Assessment of Need - Short Appraisal Schedule (CANSAS)
- The 24-Item Short Form Health Survey (SF24)
- Depression Anxiety Stress Scales (DASS)
- Resource Utilisation Groups – Activities of Daily Living Scale (RUG-ADL)
- Children's Global Assessment Scale (CGAS)
- Mental Health Inventory (MHI)
- Behaviour and Symptom Identification Scale 32 (BASIS-32®)
- Strengths and Difficulties Questionnaire (SDQ)
- The 12-Item Short Form Health Survey (SF12)
- Global Assessment of Functioning Scale (GAF)

Table 5 highlights the four main outcome measures identified as being commonly used by survey respondents of Type 1 and Type 2 CMOs.

---

[8] Social Policy Research Centre, *Stage 1 Evaluation Report Housing and Accommodation Support Initiative (HASI*), 2007

Table 5: ***Predominant Outcome Measures currently used by CMOs***

CMO Type	**Type 1** *Mental health services only*	**Type 2** *Some mental health services*
Outcomes monitoring	DASS K10+ HoNOS GAF	DASS K10+ CANSAS HoNOS

Given the diversity of the CMO sector there is, as expected, a wide range of outcome measures.

Figure 5 gives examples of additional CMO sector outcome measures that have been identified as separate to those measures listed in the Sector Mapping Survey above.

Figure 5: Additional Outcome Measures by CMOs

"This challenge is not unique to Australia, as the international Health Technology Assessment community is also facing many of these issues".[9]

Capacity of CMOs, and Value of Data Collection

During the development of the CDS, the working group identified several data collection concerns that impact on the effectiveness of the quality of services being delivered. These are:

- Some CMOs have little or no IT infrastructure for data collection, or are using older technology. This may be as a result of insufficient financial resources, inability to manage IT change or a lack of training on the role of data collection in demonstrating organisational accountability, and enhancing consumer outcomes.
- Anecdotal reports from some CMOs indicate that the data collected is not sufficiently meaningful for the organisation, or does not demonstrate benefits for consumers. Data collection and reporting is then perceived as meeting funding body requirements only.
- CMOs need to be able to use the data they collect. For example, having the capacity to de-identify data for research projects, exchange data with other CMOs to monitor partnership progress on joint projects, for benchmarking or to have the capacity to capture critical incident management and monitoring.

Better data will improve understanding of how Not-For-Profits enhance community wellbeing and facilitate macro-level analysis of policy effectiveness.[10]

---

[9] Department of Health and Ageing, *Review of Health Technology Assessment in Australia, A Discussion Paper,* 2009, p9

[10] Australian Government Productivity Commission, *Contribution of the Not-For-Profit Sector,* Research Report, Canberra, January 2010, p LV1

5.1.3 Systems Working Group

The Systems Working Group of the Data Management Strategy commenced in April 2009 and met 11 times over a period of seven months. The group reviewed 11 commercially developed databases that were considered appropriate for use by large, medium and small mental health CMOs. See list of databases reviewed at the end of this section.

The working group worked closely with the Minimum Data Set Working Group to ensure that key operational aspects were included in the preferred data systems, such as critical incident management monitoring, and capacity to collect multiple outcome measures. The group reviewed relevant documents, such as NCOSS *A Short Guide to Choosing, Costing & Implementing a Client Management System (CMS)* 2006.

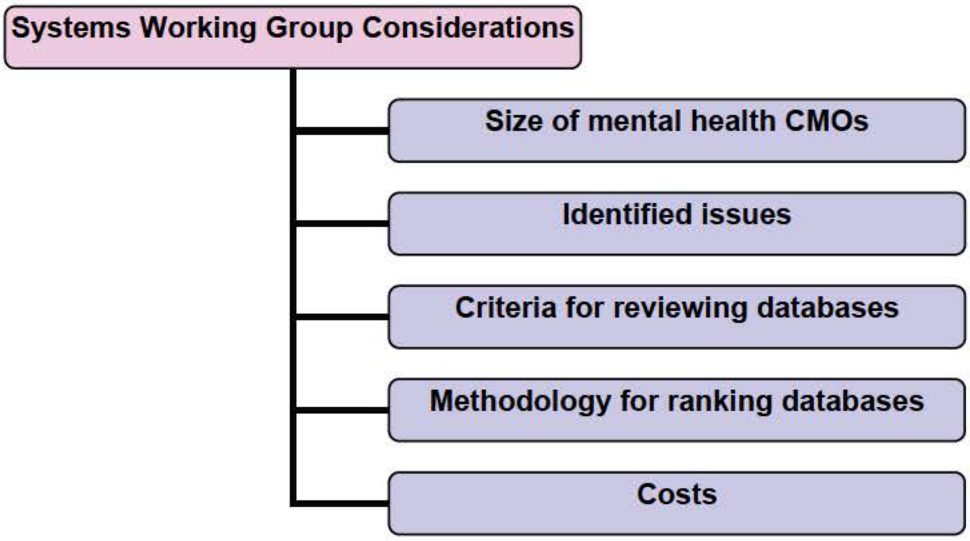
Aim of the Systems Working Group

The Systems Working Group aims to:

1. Seek to review data management systems that have quality performance management processes, were innovative, affordable and accessible.
2. Develop essential selection criteria for the assessment of suitable databases.
3. Appraise existing databases in use by mental health CMOs using the essential criteria matrix.
4. Conduct an analysis and review of Sector Mapping survey data.

Databases need to be efficient, effective and have the ability to import and extract appropriate data to enhance service provision, inform quality improvement activities, provide data to funders and assist with future growth of CMOs.

The working group considered the following factors:



Size of Mental Health CMOs

The working group evaluated the database systems in the context of the diverse size of CMOs working in mental health. It was assumed that large CMOs would have different systems needs than smaller CMOs. The group sought information from MHCC's Sector Mapping Project, which had recently surveyed mental health and other CMOs in NSW, asking about current data systems.

Table 6 shows the size and number of CMOs that participated in the Sector Mapping Survey. Note peak bodies have been removed.

Table 6: Size and Number of Mental Health CMOs in NSW

Size of CMO	CMO Type 1	CMO Type 2	CMO Type 3	Total
Non-frontline / volunteer based = 0 FTE	4	26	45	75
Small = 1 – 4 FTE	6	25	12	43
Medium = 5 – 19 FTE	5	20	13	38
Large = 20+ FTE	15	21	7	43
Total	**30**	**92**	**77**	**199**
FTE = Full time equivalent staff positions	5 Type 1 CMOs did not answer this question	10 Type 2 CMOs did not answer this question	33 Type 3 CMOs did not answer this question	247

Identified Issues

During the process of evaluating options, the working group identified a range of issues affecting the capacity of the sector to adopt best practice database systems. These issues were identified as:

- The membership of the working groups was not a representative sample of CMOs in the sector, with groups consisting of staff from larger organisations that are able to involve staff in the development process. Staff from smaller CMOs had expressed an interest in the DMS project but had been unable to be actively involved due to a lack of resources. A small number of NGOs remained on the e-mailing list.
- CMOs are at different levels in the use of database systems.
- There is a wide range of data management systems in use across NSW.
- CMOs use a combination of computerized and manual recording systems.

- Some CMOs have paper-based systems, whereas others have purpose-built databases. Some databases are software packages modified for the specific needs of the CMO, and others are developed in-house using MS Office packages.
- Other CMOs have several systems for different functions, which may be a combination of purpose-built and paper-based.

- There are technical limitations. In some cases, database systems do not integrate with other IT systems, and there are rural locations with connection difficulties. Some databases are unable to be modified as the organisation grows, or if the CMO wants to collect and analyse new data.
- CMOs that rely on external technical backup and support may find that assistance is inconsistent, inaccessible or cost-prohibitive.
- Data previously collected through the Sector Mapping Project was not specific enough to evaluate exactly what type of systems CMOs are currently using or what their database requirements are.

Other factors that affect CMOs are:

  - Funding bodies have different requirements for database systems, making it difficult for CMOs with multiple funding sources to comply.
  - There is significant cost, and logistical issues associated with introducing new data management systems across NSW.
  - Data is not currently centralised thereby limiting the capacity for the sector to undertake planning for future growth and research.

Criteria for Reviewing Databases

The Systems Working Group developed a 24-item Database Essential Criteria Matrix based on the NCOSS[11] document. The working group using the matrix conducted a thorough assessment of each of the databases.

The items of the Database Essential Criteria Matrix are:

Table 7: Database Essential Criteria Matrix

	Database Essential Criteria
1.	Web-based database with connectivity across whole state
2.	Infrastructure/ technology minimum requirements – platform independent
3.	Server: a. Self-Host or Developer Hosted b. Costs – one off or per annum
4.	Program of live upgrades and updated versions incorporate specific changes
5.	Data Safety and Back-up: a. Method b. Restore Time c. Costs - Maintenance and Repair
6.	Ease of use
7.	Flexible to fulfil individual CMO needs
8.	Comprehensive data set requirements
9.	Capacity for electronic referrals
10.	Importing and exporting of data and client information (if required): a. Internal b. External
11.	Ability to export MDS data to funding bodies - To which funders
12.	Client notes, entry and exits, hours of support recorded etc.
13.	Security authorizations built in with integrity
14.	Reporting: a. Research and planning capacity, with analysis capability – service-related b. Generate relevant individual client and CMO service reports
15.	Ability to scan and attach documents to existing clients' information
16.	Ability to accommodate multiple outcome measures, scores and generate graphs and reports

---

[11] NCOSS, *A Short Guide to Choosing, Costing & Implementing a Client Management System (CMS)*, 2006

	Database Essential Criteria
17.	Ability of CMO to add or remove fields
18.	Ongoing, accessible system support
19.	Affordable: a. Software package costs b. Subscription costs – fee per user or fee per log in 'at any one time' c. Maintenance/ IT support costs Full time equivalent versus concurrent use
20.	Workforce training requirements: a. In-house or external b. Costs
21.	Ability to accommodate future integrated payroll, finance and HR system
22.	Client Needs & Privacy: a. Privacy maintained? How? b. Who has control of User name/ Password assignment? c. Files/ transactions encrypted d. Who will have access to files in un-encrypted form? e. What guarantee re developer authorized staff misusing files/ data?
23.	Easy Conversion: a. Staff time required to convert files b. Down time – how long service shut c. Migration included in cost
24.	End of Contract: a. Ownership of data b. Format of data return c. Timeframe for return of data

Methodology for Ranking Databases

The working group directly contacted the database developers, organised appointments and advised the reason and purpose of the demonstration to recommend to the CMO mental health sector. Individual group members were assigned databases and asked to complete the criteria matrix and gather information at the demonstration. Additional contact occurred at a later date if further information was required. The working group had the opportunity to see a working version of all but one of the databases, and considered the maturity of development of the programming, and the degree to which the database was able to meet the level of completeness and flexibility required by the mental health CMO sector.

During the review process, several criteria were regarded as essential components, which were used to rank the databases' suitability, including:

- Whether further database development was required to be specific to the CMO mental health sector - as several databases were tailored to the disability sector
- Cost per concurrent user (as opposed to each user)
- Completeness – allowing for a diverse range of CMOs to use the database without significant adaptation.

A full methodology for ranking databases can be seen in Appendix L.

The databases evaluated by the group are listed in Table 8 below.

Table 8: Databases Reviewed

	Database	**Developer**	**State / Country**
1	*Amanda*	NoCode IOS360	Queensland
2	*Carelink+*	Icon Global	Victoria
3	CIMS*ability*	CIMS*ability*	NSW
4	*CSnet®*	Community Link	Queensland
5	*Dewacorp*	Dewacorp	NSW
6	*Frameworki*	Corelogic	United Kingdom
7	*Gemma*	Castle Personnel	NSW
8	*Insite*	NoCode IOS360	Queensland
9	*MACSIMS*	FlowConnect	NSW
10	*Medical Director*	Health Communication Network	NSW
11	*Recordbase*	Wild Bamboo Ltd	New Zealand

Costs

The Systems Working Group explored through IT suppliers the probable costs for CMOs to establish new data systems (based on average costs). The group also identified additional costs that are difficult to estimate, as they are dependent on market forces and the specific requirements of each CMO.

Costs relate to the following factors:

- Data storage - access to the database via web, or a stand-alone computer/ server
- Internet connection and speed
- Installation costs of new or upgraded equipment, software and licenses
- Platform compatibility depending on whether the CMO uses PC or Apple Mac
- Development of an implementation plan to ensure commitment of Board, staff and volunteers
- Training of staff and backfilling
- Ongoing IT support

Corporate Licenses

The availability and cost for a corporate license was considered by the group as an avenue to assist smaller CMOs who may find license costs prohibitive. The two recommended database developers were approached to provide an estimation of costs so the group could determine feasibility of this approach. The following information was received from the developers.

Offer 1 Icon Global Carelink+

Icon Global proposed pricing for *Carelink*+ for the smaller MHCC member organisations, having less than 10 users and for a standard system, i.e. no customisations. The offer would be through MHCC as a corporate licensing scheme whereby the member organisations buy the user licenses and the annual maintenance is paid for by MHCC, which gives member organisations support and quarterly updates.

Training would be offered centrally through MHCC, with any organisation able to attend any session, which would be offered regularly based on demand, at a daily cost which MHCC can recharge per participant at the rate it considers appropriate.

Icon Global's offer is as follows:

	Concurrent User Licensing					
Organisations' Offer	1	2	3	4	5	10
Carelink+ license which includes: ≠ Online manual ≠ Client, Employee (HR), roster & reporting features ≠ Case Management module ≠ DEEWR, HASI, Basic32 & CANSAS Reports ≠ 1 day project consulting*	$7,500	10,000	12,000	13,500	15,000	20,000
MHCC Offer Training - max 5 per course System Administrator - 1 day User (1 Day) Customised sessions e.g. advanced rostering	 $1,500 $1,500 $1,500					

Annual Maintenance at Platinum Level	
40 Users	17,850
80 Users	21,000
200 Users	29,425
300 Users	35,700
400 Users	42,000
500 Users	48,300

* Organisations would need to consult with Icon Global implementation experts on how to assist with optimal set-up after they have undertaken training. Travel is not included in the above offer and would be reimbursable.

Individual organisations could ‘option up’ on additional features such as Facility Option (event/site rosters) and Complaints Register or obtain more consulting time that could include data conversion if they have existing databases. *Carelink+* can also be interfaced to payroll and finance systems but that is an optional extra.

The Annual Maintenance at Platinum level provides unlimited support hours. Icon Global will negotiate the cost as can customize the features of the Platinum level to suit MHCC.

Offer 2 Corelogic Frameworki

Corelogic would grant MHCC a non-exclusive, non-transferable licence in perpetuity to use *Frameworki* for a fee for the MHCC itself to use, or for any members of the MHCC, up to a licensed limit of 200 named users.

This will allow MHCC or any number of its member organisations to use *Frameworki* in a comparable way to that of the SFNSW. 200 named users could cover 10 organisations that are part of the MHCC umbrella with more licenses able to be acquired in due course should they be required.

Corelogic would supply *Frameworki,* provide remote and on-site support for the implementation and also provide remote support for the application. MHCC would in turn provide a project team to support the implementation locally and provide first-line support to users when live. Corelogic would provide second-line support in the event of a technical issue arising that requires resolution.

Both Corelogic and MHCC would recognise that *Frameworki* would need to be implemented remotely with only some on-site support and that the time differences will, on occasions, make communications challenging. MHCC would bear the cost of any third-party software and support required to run *Frameworki* along with any hardware plus the costs of any personnel that may need to be employed to support the implementation and on-going first line support for end-users.

A license to use *Frameworki* on the terms outlined would be £40,000 (Approx. $65,000 AUD) plus any relevant taxes. This would be a fixed price cost that covers the license and the consultancy and technical support required from Corelogic to achieve a successful go-live. 50% would be paid on contract and 50% on go-live at which point an annual support fee of £16,000 (Approx. $25,000 AUD) plus relevant taxes would be paid in advance. All travel and subsistence would be included at no extra cost.

Database Recommendations

The working group was unanimous in its recommendation. On the criteria of development maturity, and the meeting of all other criteria one database was demonstrated as being superior i.e. *Carelink+.* It is a mature application with many features built in and has had extensive development for the mental health CMO sector. The ability to turn off features and data collection elements that are not required and the cost-effectiveness of the product mean that it is suitable for the large, medium and small organisations that comprise the MHCC member base.

The alternate database system considered by members of the group to also be suitable for the CMO sector is Corelogic *Frameworki.*

"You can have data without information, but you cannot have information without data." Daniel Keys Moran

5.1.3 Data Dictionary Working Group

The Data Dictionary Working Group commenced later in the project, July 2009, with the assistance of a Consultant to develop a draft CMO Mental Health Data Dictionary that was specific to the needs of CMOs working in mental health. The draft Data Dictionary was to complement the Comprehensive Data Set (see above) by providing definitions for the data set. Such standardisation would optimise the quality, comparability and utility of data.

A clear priority for the data dictionary was that it be user-friendly, as staff would be the most likely people to read and use the tool. The group also confirmed its underlying philosophy that the data dictionary should have a consumer/ carer focus.

The group reviewed several relevant existing data dictionaries, to identify which terms were applicable in their current form to the mental health CMO sector, and which were not. It determined that where there was a need to depart from the existing data definitions, it would develop inclusion/ exclusion rationales and provide an explanation why a data element is not relevant or required adaptation. Also included would be meanings and interpretations of a concept if different in the mental health CMO sector. For example, the term 'client' requires different definitions when referring to a carer or to a person living with a mental illness and receiving services.

The existing data dictionaries reviewed by the working group are:

- Australian Institute of Health and Welfare, *National Health Data Dictionary*
- Australian Institute of Health and Welfare, *National Community Services Data Dictionary*
- NSW Health, *Data Dictionary and Collection Guidelines for the NSW Minimum Data Set for Drug and Alcohol Treatment Services 2004-05*
- *Western Australian/ Victorian Mental Health NGO Data Dictionary*
- *Psychiatric Disability Rehabilitation and Support Services Data Dictionary.*

The working group also reviewed a range of guidelines and journals to assist in its task. Two listed as examples are:

- AIHW, 2007, *A guide to data development*
- AIHW, 2006, *Cutting the red tape: Preliminary paper detailing the problem of multiple entry and reporting by service providers*

The Data Dictionary Working Group met on five occasions and began by developing a shared definition of the term 'data dictionary'. It considered the following:

- How significant is the data to be collected?
- What was a data dictionary to look like, and describe its purpose?

- How would it be presented?

Members worked closely with the MDS Working Group and the Systems Working Group (a number of members were on both the MDS and the Data Dictionary Working Group) to ensure consistent terminology and specific adaptation of the CDS. The group also explored the potential for the database system to have a drop-down data dictionary term for each specific data field. It was determined that the data dictionary could be both paper-based and electronic, dependent on the size and complexity of the data set.

During the development of the draft domains of the data dictionary, the group determined that there was a risk the document was too technical for use by CMOs. The group sought advice from staff of the Australian Institute of Health and Welfare in relation to the continuation of development of the Data Dictionary. As a result, the working group members decided that a User Manual would be a more appropriate format to assist the recording of data information.

In January 2010 the MDS and Data Dictionary Working Groups were combined with the focus on the completion of the proposed CDS and MDS for the sector. The group had determined the development of a User Manual be considered in phase two of this project, i.e. if at all required as it is dependent on the database not having its own user manual. Initial discussions occurred with database developers who advised that data systems do have their own user manuals, and that the CDS could be integrated into existing database systems.

We're entering a new world in which data may be more important than software. Tim O'Reilly

5.2 Issues for implementation – Challenges, Risks and Opportunities

This project identified a range of issues that affect the implementation of data systems development in the CMO mental health sector in NSW. These issues relate to the following:

- Challenges - that are complex
- Administrative burden
- Risks - that may inhibit systems development
- Opportunities - that currently exists and can be better used for systems development.

Challenges

The Australian Public Services Commission (APSC) describes challenges as having both vertical (relating to accountability) and horizontal (relating to flexibility and collaboration) elements. Both are necessary, however over-accountability limits innovation, and too much flexibility limits information about performance.

The APSC considers that in the context of multi-funding sources and reporting requirements, there will need to be a high investment in NGOs to develop systems, network applications and skills to enable national data to be useful for comparative analysis.[12]

This project identifies several significant challenges affecting the implementation of a comprehensive data management system for mental health CMOs. These are:

- CMOs are at different stages of data management system development. This is due to several factors:
    - Lack of a holistic national or state approach to CMO systems development.
    - Each program determines what data is to be collected by CMOs.
    - Lack of specifically designed systems that are applicable to all types of mental health CMOs, contributing to the ad hoc development of different systems. This has resulted in information gaps; areas of duplication and lack of knowledge about whether the CMO programs meet the services' purpose, or consumer outcomes have improved.
    - Varying levels of understanding or in-depth knowledge in mental health CMOs about the benefits of technology for improving service performance and accountability. Some CMOs have paper-based data management systems.

---

[12] Australian Public Service Commission, *Policy Implementation through Devolved Government* 2009, p21

  - Lack of precise information about the type of systems NSW mental health CMOs are currently using and their IT infrastructure requirements, and the subsequent costs and logistical issues associated with introducing new or upgraded database systems across NSW.

  - The dearth of research into evidence based practices within the CMO sector or a state/national mental health CMO Research and Evaluation Framework.

  - The absence of a national mental health CMO clearinghouse.

An example of an effective clearinghouse is the DrugInfo Clearinghouse, which functions as a drug prevention network, providing easy access to information about alcohol and other drugs, and drug prevention. The DrugInfo Clearinghouse collects, interprets and disseminates information on drug prevention DrugInfo Clearinghouse is a service provided by the Australian Drug Foundation (ADF). The core purposes of the ADF are to prevent drug problems and reduce drug-related harms; and to help people remain safe if, when and while they use drugs.

It is recommended that MHCC commence discussions with Community Mental Health Australia regarding the establishment of a national mental health CMO clearinghouse. This organisation would collect best practice from mental health CMOs, which would be publicly available to members, the sector and funding bodies.

Zimmermann at the 2009 MHCC/ NADA Conference discussed the need for sector research and a clear research framework. '*Research involves the creation of new knowledge to inform the delivery and improvement of services. Research can involve elements of risk, which need to be mitigated. Part of mitigating this risk is to ensure there are proper safeguards and practices in place to ensure effective conduct of research. This involves transparent decision-making processes, clear allocation of responsibilities and robust monitoring arrangements.*

A clear Research and Evaluation Framework is a vital tool for guiding, facilitating and integrating research and evaluation activities. It provides an opportunity to develop and promote knowledge and understanding of effective mental health services by highlighting the central role that research and evaluation can play in improving services and consumer outcomes.'[13]

- There are also technical limitations, such as:
  - Some existing database systems do not integrate with other ICT systems.
  - Regional, rural and remote locations have internet connection difficulties.
  - Some existing databases cannot be modified as the organisation grows, or if the CMO wants to collect and analyse new data.

---

[13] Zimmermann, A., *Developing Research Capacity in a Community Based Mental Health Agency: Neami Research Framework*, Neami, paper, MHCC/NADA Conference 2009

  - External technical backup companies may be inconsistent, inaccessible or cost prohibitive for some CMOs.

- Funding bodies have different requirements for data collection and reporting, which places administrative burdens on CMOs with multiple funding sources.
- There are a number of cross-border CMOs that provide services in more than one state. This compounds any existing burden.
- Data about the mental health CMO sector is fragmented, as it is provided to different funders with no data exchange protocols between those funders. The lack of cross-government collaboration means that data is not currently aggregated, which limits the capacity of the sector to undertake planning for future growth and research.
- The lack of sector data is amplified by the absence of sector research, benchmarking and best practice guidelines.
- There are a number of significant data collection changes currently being explored that as yet, have unknown implications for the sector. Some partnership projects such as the Housing and Supported Accommodation Initiative (HASI) require that CMOs include NSW Area Health Service record numbers within their collections for those individuals who are clients of both the CMO and NSW Health. This is intended to support evaluation of access to and effectiveness of these services. Such approaches will require a balance between the need to build an understanding of the whole health service system as it affects an individual consumer's total experience of care, and the need to maintain privacy for the individual.

Administrative Burden

Many CMOs working in mental health in NSW are under significant pressure, due to the diverse reporting requirements of multiple funders. There are at least 20 different funders including government departments funding mental health CMOs and most require mandatory regular reporting on a range of performance measures.

The administrative burden on CMOs to collect data and produce these reports is increasingly complex and time-consuming.

> ***"Reporting requirements associated with grants have become disproportionately more onerous without commensurate benefit"***[14]

Community service providers are carrying a considerable data collection and reporting burden. The two primary and inter-related causes of this burden are summarised as:

---

[14] Australian Government Productivity Commission, *Reforms needed for the Not-For-Profit Sector,* Media release, 14 October 2009

1. The requirement of program-centred reporting for service providers to use separate, program-provided data collection forms and/or software, resulting in the client providing, and the service provider recording and reporting, the same client variables on that client multiple times.

2. The lack of electronic data capture, storage and reporting systems in the community services sector which would give providers the capacity to record data once, from which multiple reporting could occur.[15]

Challenges for the Sector

A number of points still require consideration by the CMO sector:

1 How to ensure people living with a mental health problem, carers and the CMO sector benefit from the standardisation of data.

2 How to ensure consumer and carers' right to privacy is maintained.

3 How to provide ongoing data information and management training for consumers, carers, staff and volunteers across NSW to ensure improved outcomes for consumers, best use of data collected, security, validity and consistency of data collection.

4 How and who will collect and collate data on behalf of CMOs in NSW to seek enhancement in funding and growth in service provision.

5 How to ensure the different funding data requirements of both state and federal departments are reduced to one agreed data set for the CMO sector.

"In an increasingly evidence-based funding environment, organisations that cannot afford to invest in software, with the capacity to collect and manage the data, are at a distinct disadvantage" [16]

Risks

Governments are shifting some mental health service activities away from acute hospital and public community mental health care, and placing increasing responsibility with CMOs. Consequently there is a greater degree of potential risks and incidents.

CMOs therefore need to enhance their infrastructure, service models and data management systems to identify, inform and manage those risks. Governments also need systems in place to ensure accountability, and plan for adequate funding and resources for CMOs to manage the risks.

---

[15] Australian Institute for Health and Welfare, *Cutting the red tape: Preliminary paper detailing the problem of multiple entry and reporting by service providers,* November 2006, p6

[16] NSW Council of Social Services, *Information Technology Strategy Report: Discussion Paper,* April 2007, p4

Sophisticated data management systems that are valuable to all parties require a significant investment in resources - technology and equipment, and skills - operational and strategic.

In 2007, NCOSS identified several barriers for the human services sector:

- Funding often fails to include ICT costs. It is estimated that about 70% of costs are for ongoing upgrades, technical support, training, licenses, and administrative support
- Low levels of ICT expertise in the sector. ICT consultants do not usually have relevant experience with NGOs, and are unfamiliar with the culture, service provision and compliance requirements. This may result in higher expenditure for inadequate systems.
- Lack of independent ICT advice. Often the only available advisor is also the main supplier of ICT.
- Risks to consumer privacy. Any data system developed for external information sharing needs to maintain consumer privacy and confidentiality.[17]

"Privacy concerns and risks associated with information databases arise out of the way the information is collected and how it will be managed and used once contained on the database".[18]

In 2008, NCOSS followed up with further evaluation of the NGO sector, noting particular concerns about access for rural and remote locations to fast reliable Internet and connectivity, and access to affordable ICT advice and support.

NCOSS made the following recommendations:

1. Shared ICT support across NGOs
2. Training programs to support sustainability
3. Feasibility study of aggregated ICT services
4. NGO-specific guide for negotiating and contracting ICT services
5. Adoption of common data sets
6. ICT-specific consultation mechanisms between NGOs and government
7. Awareness and utilization of HSNet
8. Realistic ICT component in funding formulas.[19]

---

[17] NSW Council of Social Services, *The NCOSS IT Strategy Project Discussion Paper,* April 2007, p3-4

[18] Harding, E., *Privacy Impact Assessment and Commentary on the Mental Health Information Project for New Zealand Health Information Service,* February 1999, p46

[19] NSW Council of Social Services, *Community Connexions: Addressing the Information and Communication Technology Needs of the NSW Human Services Sector, Executive Summary,* December 2008 p3, 13

The DMS project identified several significant risks for the mental health CMO sector, in relation to data management systems development, as follows:

- The possibility of inadequate funding provided to CMOs to establish appropriate ICT systems, or make upgrades in response to funders' changing reporting requirements
- The potential for changes to ICT software developers with specific expertise in mental health data systems, resulting in the discontinuation of products or the closure of the company.
- The potential lack of capacity in CMOs to use the available ICT, due to limited commitment, absence of an implementation plan and/or training for users, including Board, staff, volunteers, consumers and carers.
- There may be changes for the host of the corporate licenses (which is a strategy proposed to minimise the costs for individual CMOs), as a result of loss of funding, or agency closure.
- Insufficient qualified and accessible ICT support for CMOs, either in-house or via companies, to maintain and upgrade ICT systems, is a major concern.
- Transparent data, information and feedback from funding bodies to CMOs about how data is used for planning decisions and assessing service performance may not be provided.
- CMOs may be excluded from or marginalised in the sector-wide planning and development processes.

Opportunities

It is very clear that quality data and information management systems can:

1. Assist consumer outcomes
2. Improve quality of services and performance and provide an opportunity to link outcomes to service provision
3. Enhance organisation knowledge and integrate data systems by using standardised data collection methods
4. Link to an organisations Human Resources and Occupational Health & Safety systems
5. Determine current and future growth needs
6. Meet funding requirements
7. Determine and meet specific sector needs by assisting the sector to seek increased funding, and
8. Provide research and data sharing opportunities.

This project identified several key aspects of the mental health CMO sector that will positively influence the development of comprehensive data management systems. These aspects provide opportunities for strategically enhancing the directions of ICT development in ways that will benefit mental health CMOs.

The aspects for influencing development are:

- Enhanced potential for cross-government and interagency partnerships, so that data systems reflect the needs and interests of all parties.
- An increasing awareness and recognition of the value of CMOs.
- Understanding of the benefits of effective data collection and use by the mental health CMO sector. This is demonstrated by an increasing number of mental health CMOs building their own data management systems.
- Specific mental health CMO data management systems have been developed in Western Australia and New Zealand. These systems were considered in the work of this report.
- The ICT infrastructure is rapidly changing, with greater potential to be increasingly more accessible, efficient and effective for the sector.

5.3 Data Systems Development for the Future

During this project, MHCC identified key areas for further development, and submitted a proposal to NSW Health recommending the continuation of work already commenced in developing sector-wide technology, and for a systematic data collection and reporting framework for CMOs working in mental health in NSW. This proposal was funded in 2010 and is known as the Data Management Strategy Phase 2.

Data Management Strategy - Phase 2

Phase 2 of the Data Management Strategy is to partner with key stakeholders: MHCC members, InforMH (NSW Health's Mental Health Information Unit), and NADA (peak body for drug and alcohol services) to realise an effective and efficient rollout of a Data Management Strategy for community organisations working in mental health in NSW.

Strategies for Phase 2 include:

- Establishment of a Data Management Strategy Phase 2 Advisory Committee.
- A scoping study of the information technology infrastructure and data system development requirements of MHCC member agencies.
- Identification of member agencies (small, medium and large CMOs) to be involved in a case study approach to the use of the Comprehensive Data Set.
- Development of a multi-pronged sector-wide Implementation and Communication Plan to broadly engage mental health, community and public sector agencies in the project aims and outcomes.
- Development of a Business Plan outlining the process and costs required to enhance and support CMOs information technology infrastructure.
- Integration of the CDS, including user manuals with recommended database systems.
- MHCC to review and complement the work of the Australian Institute of Health and Welfare in seeking a national Agreed Minimum Data Set for CMOs.
- Development of training, promotional and resource materials to assist CMOs to implement data management systems.
- Establishment of a Data Management Network to provide a forum for CMOs to determine an agreed minimum data set, continue systems development and a sector approach to data management.
- MHCC participation in Mental Health and Drug and Alcohol Information Sub-Committee (MHDAIS) ensuring compatibility and collaboration with the aims of NSW Health.

> ***“Where local area information systems are designed around the information needs of service providers and their clients, the benefits are more likely to be seen to offset the data collection burden”.***[20]

---

[20] Wood, C; Pennebaker, Dr D., *The Non-Government Mental Health Services Information Project Report,* Centre for Mental Health Services Research Inc. Perth, Western Australia, October 2000 p65

6. Data Systems Development So Far

This section describes the activities undertaken by the key stakeholders in data systems development for the CMO mental health sector in NSW, i.e.:

- Australian Commonwealth Government
- NSW State Government
- Mental Health Coordinating Council
- NSW Mental Health CMOs
- Other relevant organisations

6.1 Australian Commonwealth Government Activities

The Australian government is currently considering the future directions of information and communication technology in broad terms, stating that it is a "highly dynamic field" that can shrink distance, and change how people and organisations interact. To gain the benefits, there is a need for CMOs to have maximum participation and workforce flexibility. The Department of Broadband Communications and the Digital Economy considers that key sectors of the Australian community have the following roles:

- Government – Lay the infrastructure foundations, facilitate innovation, and provide regulatory frameworks
- Industry – Develop digital confidence and skill, adopt smart technology, and develop sustainable online content/ service delivery models
- Community – Develop digital confidence and media literacy skills, participate and engage online.[21]

The Australian Institute of Health and Welfare (AIHW) is the government agency responsible for the development of national minimum data sets, including data collection, storage, linkage and usage. It oversees the Australian Health and Community Services Data Register in METeOR, the National Health Data Dictionary, and the National Community Services Data Dictionary.[22] This information can be used by all health jurisdictions to ensure consistency, standardisation and comparability of data collected.

In 2006, the Australian Institute of Health and Welfare explored the problems of multiple data collection and reporting, and found two key reasons for the considerable burden on CMOs particularly smaller CMOs, as follows:

---

[21] Department of Broadband Communications and the Digital Economy, *Australia's Digital Economy: Future Directions* 2009, p16

[22] Australian Institute of Health and Welfare, Statistical Information Management Committee (SIMC) www.aihw.gov.au/committees/simc

1. Program-centred funding models and software, which promote multiple entry, and do not support best practice case management models
2. Lack of electronic data collection, storage, and reporting systems

The AIHW recommended the development of national data standards, and that data systems be person-centred, as a way of implementing the good practice principle of "create once, use often" as it relates to information management.[23]

Study in Point

The Schizophrenia Fellowship of NSW Inc. is a large CMO, and is funded by, and provides regular reports to the following organisations:

- NSW Department of Health
- Commonwealth Department of Health and Ageing
- Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs
- Commonwealth Department Employment Education and Training
- NSW Department of Sport and Recreation
- Various private and company donations[24]

AIHW NGO Data Development Scoping Project 2010

During January to June 2010 the Department of Health and Ageing requested the Mental Health Services Unit of the AIHW to scope the issues, options and potential data development work required to obtain more detailed information about the specialised mental health services currently being delivered by NGOs in Australia.

The scoping project aims are to:

- Scope current mental health NGO reporting arrangements across all jurisdictions.
- Gain a better understanding of the activities of mental health NGO providers.
- Hold discussions with the Departments of Health and Ageing, and Family

---

[23] Australian Institute for Health and Welfare, *Cutting the red tape: Preliminary paper detailing the problem of multiple entry and reporting by service providers,* November 2006, p1-2

[24] Schizophrenia Fellowship of NSW Annual Report 2009

Housing, Community Services and Indigenous Affairs on their respective NGO activities.

- Identify the issues to be resolved in developing a data set to cover the mental health NGO sector.
- Identify current service delivery types in use and recommend on whether there is a basis for common or 'core' set of service types.
- Outline in broad schema form the potential data collection and reporting arrangements that might be applied to each service type.

In line with these aims the scoping exercise will focus on existing specialised mental health services delivered through the NGO sector; any existing requirements for data collection and reporting that may already exist and consider all three levels of potential data collection as follows:

1. Establishment-level data
2. Consumer-level data
3. Activity-level data

A report of the NGO Data Development Scoping Project is expected to be presented to the Mental Health Information Strategy Subcommittee in August 2010.

Third Sector Reform

The Australian government explored the role of the third sector in service delivery, with the Productivity Commission undertaking a review of the NGO sector in 2009. The report states that 600,000 NGOs in Australia are contributing $43 billion to Australia's Gross Domestic Product (GDP), and that the value of 4.6 million volunteers in the sector is worth around $15 billion. Together, this means the NGO sector is comparable to the retail industry.

The Commission identified in the not-for-profit sector the following point:

> ***"Many offer their participants opportunities to build a sense of self worth and for connection and influence that form an important part of the foundations of an active civil society."***[25]

The Productivity Commission report also recognised the need to reduce the administrative burden and current information requirements imposed on NGOs, and proposed a range of actions, including:

---

[25] Australian Government Productivity Commission, *Contribution of the Not-For-Profit Sector,* Research Report, Canberra, January 2010, Overview XXV

- A nationally agreed measurement and evaluation framework for outcomes and impacts on the sector.
- Establishment of a Centre for Community Service Effectiveness to improve knowledge on good evaluation practice, and assemble and disseminate evaluations based on the agreed measurement framework.
- Implementation of government and sector reforms will be best facilitated by a central policy and implementation unit within the Australian government such as through the establishment of a specific Office for Not-for-Profit Sector Engagement.[26]

A report in 2009 by the Australian Public Service Commission shows an increasing trend for the Commonwealth government to devolve services to the non-government sector, from $15.43 billion (35.1% of expenditure) in 2006-07, up to $18.08 billion (36%) in 2007-08.[27]

The Department of Families, Housing, Community Services and Indigenous Affairs also has a compact for the relationship between the Australian government and the third sector, proposing principles based on respect, inclusion, diversity, effectiveness, efficiency and sustainability. It considers key efficiency issues to be addressed including the need to reduce red tape, streamline reports, develop best practice guidelines, and reduce the regulatory burden on the NGO sector.[28]

Data Management in the General Health Sector

Australian Health Ministers have introduced a national project known as *e-Health*. This project includes the electronic collection and exchange of patient and health provider data through the allocation of unique individual identifiers.

However, there are considerable concerns about privacy and confidentiality with legislative implications.[29] It is not yet known how CMOs working in mental health will participate in this project.

In 2009, the Department of Health and Ageing reviewed its health technology, and identified key aims for improvement, including:

- Reduced fragmentation
- Duplication and unnecessary complexity, and
- Improving transparency of health assessments and decision-making.[30]

---

[26] Australian Government Productivity Commission, *Contribution of the Not-For-Profit Sector,* Research Report, Canberra, January 2010, p367

[27] Australian Public Service Commission, *Policy Implementation through Devolved Government* 2009, p8-9

[28] Attorney General's Department, *National Compact Consultation Paper: Engage: A new relationship between the Australian government and the Third Sector,* 2009, Australian Government

[29] Australian Health Ministers' Advisory Council, *Healthcare identifiers and privacy: Discussion paper on proposals for legislative support,* July 2009, p3

Data Management in the Mental Health Sector

Since 1991, the Australian government has undertaken a range of activities to reform mental health services. Appendix F shows some of the key documents in mental health in the past two decades.

Some key outcomes to date are:

- Introducing routine consumer outcome measurement in all government mental health services
- National performance indicators for public mental health services and service level benchmarking
- National minimum data sets for all aspects of public mental health service delivery
- Population-based surveys to monitor the prevalence of mental illness in the Australian community.[31]

Since 1992, the Commonwealth Department of Health and Ageing (DOHA) has collected outcomes data under the National Mental Health Strategy. Data is primarily used by clinicians to monitor consumers' health and wellbeing, and by governments to monitor broader service outcomes.[32]

In 2009, DOHA recognised there are still difficulties with interpreting data, due to the impact of casemix on variable data results for public health services and consumer groups. This means that there are different outcomes between similar services for consumer groups. To overcome this problem, DOHA has proposed that a risk adjustment approach be used to apply controls for aspects of group differences.[33] For example, there was a challenge for data interpretation, as variable consumer results were identified between organisations providing similar types of services.[34]

All Australian public mental health services are required to routinely administer clinician and consumer-rated outcome measures at admission, review (at 91 days), and at discharge.[35] In 2007, the National Mental Health Performance Subcommittee reviewed the implementation of national key performance indicators for data

---

[30] Department of Health and Ageing, *Review of Health Technology Assessment in Australia: A discussion paper, 2009*, p3

[31] Commonwealth of Australia, *Fourth National Mental Health Plan 2009-2014,* p37

[32] Department of Health and Ageing, *National Outcomes and Casemix Collection: Programs,* 19 January 2001

[33] National Mental Health Performance Subcommittee, *Australian Mental Health Outcomes and Classification Network Update,* Agenda Paper 12, 2-3 April 2009, p2

[34] Burgess, P' Pirkis, J., *Case complexity adjustment and mental health outcomes: Conceptual issues,* National Mental Health Performance Subcommittee*,* Agenda Paper 12, 2-3 April 2009, p2

[35] Burgess, P., Pirkis, J., *Case complexity adjustment and mental health outcomes: Conceptual issues* National Mental Health Performance Subcommittee, Agenda Paper 12, 2-3 April 2009, p1

collection and reporting by public mental health services in each state, and found a number of problems at service delivery level.[36]

The Fourth National Mental Health Plan 2009-2014 identifies significant shifts in the mental health sector since the previous plan, as follows:

- Growth of community-based services
- Growing awareness of the prevalence and impact of mental health across the lifespan
- Importance of other sectors for improving mental health, such as housing, education and employment.[37]

The Fourth National Mental Health Plan focuses on five priority areas for reform, i.e.:

1. Social inclusion and recovery
2. Prevention and early intervention
3. Service access, coordination and continuity of care
4. Quality improvement and innovation
5. Accountability – measuring and reporting progress

All of the above priority areas relate to CMOs working in mental health in NSW.

For example the following Table 2 is an extract from the Plan showing the outcomes and actions for Priority Area 5 - Accountability.[38]

---

[36] National Mental Health Performance Subcommittee, *Implementation of KPIs and future directions,* Agenda Paper 5, 2-3 April 2009

[37] Commonwealth of Australia, *Fourth National Mental Health Plan 2009-2014 A discussion paper,* February 2009, p3

[38] Commonwealth of Australia, *Fourth National Mental Health Plan 2009-14,* pviii, 61

Table 2: Priority Area 5 of Fourth National Mental Health Plan

Priority 5: Accountability – measuring and reporting progress	
Outcomes	**Actions**
The public will be able to make informed judgments about the extent of mental health reform in Australia, including the progress of this Fourth Plan, and have confidence in the information available to make these judgments.	Build an accountable service delivery system that monitors its performance on service quality indicators, and makes this information available to consumers and other stakeholders.
Consumers and carers will have access to information about the performance of services responsible for their care across the range of health quality domains and be able to compare these to national benchmarks.	Further develop mental health information, including national mental health data collections that provide the foundation for system accountability and reporting. Conduct a rigorous evaluation of the Fourth National Mental Health Plan.
Key indicators Proportion of services publicly reporting performance data.	

The Australian government recognises that further development is required to address the following issues:

- Data is not readily available
- There are gaps in the information collected in particular consumer satisfaction [of services]
- There is a lack of recovery-based outcome measures in the NGO sector
- Consumers and stakeholders do not have readily available information about local mental health services.[39]

Recovery-Oriented Service Provision in Australia

Recovery is *"described as a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness"* (Anthony, 1993 in the National Mental Health Plan 2003-2008)

---

[39] Fourth National Mental Health Plan, *Fourth National Mental Health Plan 2009-2014,* Draft 19 April 2009, p37

Recovery-oriented service provision in Australia is recognised in the National Mental Health Plan 2003-2008, and indicates that "*a recovery orientation should drive service delivery*". Recovery is also a central focus in the NSW Community Mental Health Strategy 2007-2012, that seeks to "*embed a recovery approach within service delivery*".[40]

Study in Point

Psychiatric Rehabilitation Australia (PRA) is a large CMO providing support services for people living with mental illness throughout NSW and south eastern Queensland.

PRA receives funding from seven separate government departments, each requiring quarterly reports.

At the time of this report PRA is producing each quarter seven MDS reports, and seven Key Performance Indicators' (KPIs) Reports.

Much of the data is similar, but is required in different formats. The administrative burden is extensive.

The adoption of a minimum data set and standard KPIs, accepted by all mental health funders, would significantly reduce the burden and improve PRA capacity to efficiently generate reports to meet the different requirements.

---

[40] New South Wales Consumer Advisory Group - Mental Health Inc. (NSW CAG) http://mentalhealth.sitesuite.ws/page/recovery_forum_project.html

6.2 NSW State Government Activities

For many years, NSW Health has promoted the development of data management systems for the Drug and Alcohol, and Mental Health sectors that it funds. The 2009 draft review of the NGO sector by NSW Health identifies strategies to improve the alignment of NGO services to community needs, including reducing red tape and administrative burden, and improving governance, transparency and efficiency.[41]

Drug and Alcohol NGO Sector

NGOs providing drug and alcohol treatment services in NSW are required to collect and report data. There is a national and a NSW Minimum Data Set collection, with the NSW Minimum Data Set containing all the data items of the National MDS plus additional items. In 2000, the Network of Alcohol and Other Drug Agencies (NADA) was funded by NSW Health to commence a data collection system for drug and alcohol treatment services, in compliance with national data collection and evaluation by the AIHW.

While an important step forward, NSW Health recognises there are limitations (for government and non-government community-based services) such as the lack of outcome measures, no unique patient identifier, and poor capture of continuity of care for long-term clients, and other specific groups.[42] In 2005 in NSW, data collection guidelines and a data dictionary were developed for drug and alcohol services.[43]

Data collection guidelines also exist at the national level for the National MDS and are upgraded annually. As at 2007, the NSW data set had 36 items. A NADA Baseline Evaluation report conducted as a consultation to inform planning in the NGO Information Management Project found that the Minimum Data Set has established baseline data, and provides some useful information for external reporting requirements, and internal service and treatment planning. However, gaps in standardized information management in the sector still exist such as assessing consumer outcomes and co-morbidity.[44]

In 2008 NADA commenced a consultation with the sector as part of the project establishment phase of the NGO Drug and Alcohol and Mental Health Information Management Project, to determine standard outcome measurement tools, networking and training needs of the sector, and to determine enhancement of workforce capacity.[45] This work will have specific relevance to CMOs working in mental health in NSW.
See Appendix D for further information on the Drug and Alcohol NGO Sector.

---

[41] NSW Health, *NGO Review: Background Information,* 2009, p1

[42] NSW Health, *Drug and alcohol treatment services in NSW 2005-06: Annual Report on the NSW minimum data set,* 2007, p1

[43] NSW Health, *Data Dictionary and Collection Guidelines for the NSW MDS for Drug and Alcohol Treatment Services,* Version 4, 2005

[44] EJD Consulting and Associates, *Baseline Evaluation Report, NADA: Drug and Alcohol Mental Health Information Project,* September 2009

[45] Network of Alcohol and Other Drug Agencies, *Determining the Treatment Outcomes Data Collection Set.* NGO Drug and Alcohol and Mental Health Information Management Project, August 2009, p6

Mental Health CMO Sector

NSW Health has progressed data collection improvements specifically for the NGO mental health sector. In 2006, NSW Health funded the MHCC to undertake various projects to develop the capacity of NGOs working in mental health, including ICT development. See point 6.3 – *MHCC Activities* below for details.

NSW Health funded the Social Policy Research Centre at the University of NSW, which provided an evaluation report in 2007 on Stage 1 of the Housing and Accommodation Support Initiative (HASI) program. Using a longitudinal research method and standard outcome measurement tools (PWI, GAF, HoNOS, LSP-16d, and K10+LM), the evaluation found significant client outcomes were achieved, and also identified several evidence-based good practices by CMOs.[46]

Since 2001, NSW Health has required all HASI programs to collect consumer outcomes measurement data at admission, review, and discharge.

The tools used by NSW HASI programs are:

- Adults – HoNOS, LSP-16, K10+
- Older people – HoNOS65+, RUG-ADL, LSP-16, K10+LM or K10-L3D.[47]

In 2009, NSW engaged the data analyst company ARTD, which produced a document for carers about NSW Health's pilot data monitoring system, using the DASS outcome measurement tool.[48]

There is no standard data management system or outcome measurement tool used by all mental health CMOs in NSW. However NSW Health is currently undertaking a review of the HASI and RRSP programs with changes being made to the data collection requirements of CMOs.

---

[46] Social Policy Research Centre, *Stage 1 Evaluation Report: HASI,* University of NSW 2007

[47] NSW Health, *Mental Health outcomes and assessment statistics (MH-OAT) data collection: Reporting and submission requirements*, Circular 21 June 2001

[48] ARTD, *Guidelines for Family and Carers Mental Health Program: Monitoring and Reporting System*, Version 2, January 2009

6.3 Mental Health Coordinating Council (MHCC) Activities

MHCC is active in promoting improvements to the quality of mental health CMO services in NSW. This project is one of several projects funded by NSW Health to build the capacity of the sector. Other initiatives include:

NSW Mental Health NGO Development Strategy

Between 2004 and 2007 MHCC undertook activities to develop three key aspects with the CMO mental health sector. These are:

1. Partnerships – To promote opportunities for CMOs in mental health to expand their expertise in forming and utilising partnerships for service delivery.
2. Outcome measures – To increase the use of outcome measures by mental health CMOs to assist consumers with recovery processes, and to monitor and evaluate effectiveness of service provision.
3. Workforce development – To explore the opportunities to build workforce knowledge and skills.

A key outcome of the strategy was the establishment in 2008 of the MHCC Learning and Development Unit, a Registered Training Organisation that provides a range of nationally accredited training packages. Courses for example, the Certificate IV in Mental Health and the Advanced Diploma in Community Services Management, develop the skills, knowledge base and qualifications of the workforce in mental health community-based services.

The NGO Development Strategy Report recommended a sector-wide information management strategy, and learning scholarships for staff.[49]

Infrastructure Grants Program

Between 2006 and 2009, MHCC administered $4 million of NSW Health funds under the Infrastructure Grants Program, implementing several projects to improve the quality of mental health CMOs:

1. Grants - 66 grants were provided to CMOs for a range of improvement projects, such as upgrading facilities, enhancing information and communication technology, evaluating programs, and exploring improvements to existing programs.
2. Research Grants – A joint project between MHCC and NADA provided grants to CMOs for research on mental health and drug and alcohol service delivery to improve practice. An additional aim was to enhance research capacity of the two sectors.

---

[49] Mental Health Coordinating Council, *Final Report: NGO Development Strategy Mental Health 2004-07,* June 2008

3. Outcome Measures – Progression of the routine consumer outcome monitoring project that provided familiarization and initial training on the use of outcome measures to the CMO sector. This project developed training tools for CMOs to enhance the capacity of their workforce to adopt consumer outcome measures.

4. Sector Mapping Project – Maps the scope of the mental health sector, and seeks specific information about accreditation and service improvement activities, partnerships, data collection and monitoring systems. A full report on the findings of this project is available from MHCC. The information on current data systems of CMOs working in mental health is provided in point 6.4 below.

5. Data Management Strategy – This report is one outcome of the DMS Project. Other outcomes include the development of the Comprehensive Data Set and inclusion rationales and the proposed Minimum Data Set.

NSW CAG is currently working in partnership with the Mental Health Coordinating Council on developing a recovery resource for mental health CMOs in NSW.

The aim of this project is to develop a resource to assist CMOs in achieving recovery orientation across all aspects of service provision. The resource in development is the Recovery-Oriented Services Self Assessment Toolkit (ROSSAT) that organisations can use to assess both organisational and individual worker's recovery orientation. Included in the ROSSAT are two tools: one for organisations and the other for individual workers to complete. These tools identify current practice, and opportunities for improvement to enhance recovery orientation.

The Toolkit encourages reflective practice that identifies and builds upon recovery-oriented practice on a regular basis. Consultations with consumers, carers and service providers were conducted in NSW to inform the content of the Toolkit, and shaped the six areas of focus in ROSSAT.[50]

---

[50] New South Wales Consumer Advisory Group - Mental Health Inc. (NSW CAG) http://mentalhealth.siteuite.ws/index.html

6.4 NSW CMO Activities and Current Data Systems

CMOs recognise that they need accurate and timely information about service performance and consumer outcomes, so that they can develop effective plans, and strategically position their organisations within the mental health and broader community sectors.

Over many years, CMOs working in mental health in NSW have been actively developing and enhancing the capacity of their data management systems. This has occurred in the absence of state or national guidelines about best practice or system requirements. As a result, some CMOs have sophisticated ICT systems, while others have very little.

Nevertheless, CMOs are making efforts to respond to changing conditions in funders' expectations, consumers' needs, specialist service model developments, and an ageing workforce.

Current Data Systems in NSW Mental Health CMOs

MHCC's Sector Mapping Project[51] occurred concurrently with this project. Although broader in scope than data management systems, that project identified important information about the current status of CMOs data management capacity, and indicators about the challenges for keeping pace with change.

In late 2008, MHCC developed a comprehensive survey to a wide range of CMOs in NSW. Responses were received from 278 CMOs. The survey sought a range of information about the current quality of the sector, including data management systems. The following information is from the results of that survey, and shows a mental health sector that is progressing towards improving data management systems, but is inconsistent in its collection and use of data.

CMO Types

The Sector Mapping Project categorised CMOs into three groups intended to represent the dimension of mental health CMOs from most specialised to most generalised:

> **Type 1** – providing mental health programs only
>
> **Type 2** – providing mental health programs in addition to other programs
>
> **Type 3** – providing mental health support but no specific mental health programs

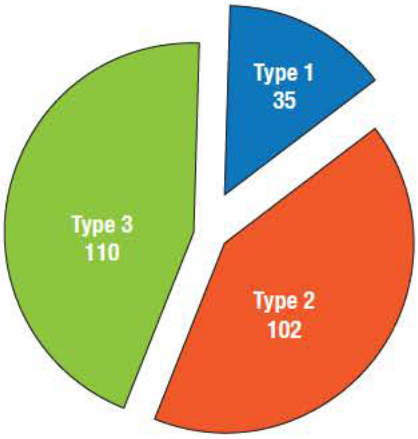


Fig. 2 CMO Types in Mapping Sample

---

[51] MHCC, *The NSW Community Managed Mental Health Sector: Report of the New South Wales Community Managed Organisation Sector Mapping Project*, 2010

Full results of the MHCC Sector Mapping Project are published in a separate report. Data tables for the summary provided below are at Appendix J.

A snapshot of relevant data from the Sector Mapping Report follows:

Services of CMOs

Table 3: Profile of CMOs Responding to Survey

Type of CMO	Number of CMOs responding to survey	Percentage of all respondents
Type 1 – CMOs providing mental health services only	35	14%
Type 2 – CMOs providing mental health and other services	102	41%
Type 3 – CMOs that do not provide mental health services, but provide support for people with mental illness	110	45%
Total	**247**	

Of the respondents, 59 CMOs provide state-wide services, 167 provide services in urban areas; 137 in rural and remote locations and 26 provide services in regional areas (both rural and urban).

The survey found a large number of previously unidentified CMOs that are not specifically funded to provide mental health services, but are modifying programs to meet the needs of mental health consumers. Survey questions related to data were directed at CMO Types 1 and 2 only.

Information Management

– Data Collection Systems

Data collection systems relate to how CMOs collect and use information about consumers and services to inform planning, monitoring and evaluation activities.

78% of responding CMOs use computers in their data collection system.

However, only 18% of responding CMOs have a fully computerised data collection system, with 60% having a combined

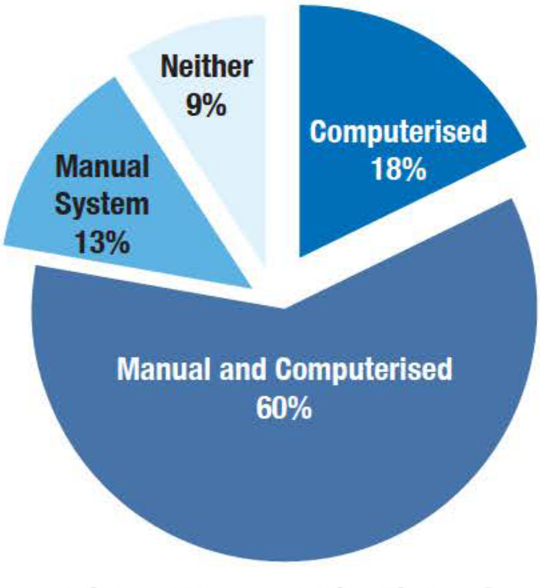


Fig. 3 Computerisation of Data Collection Systems

manual and computerised system. Computerised systems are essential for CMOs to effectively administer resources, plan strategically, and to report to many Government funding bodies.

Type of Data Collected

Most CMOs collect data about clients' personal details, the referral source, services provided and mental health diagnosis. However, there is less consistency collecting data such as client functional assessments, progress monitoring or amount of time assistance is provided.

More than 80% of responding CMOs for the Sector Mapping Project reported collecting data, as shown:

Client personal information = 85%
Referral sources = 82%
Type of assistance provided = 81%

Outcome Measures

K10+ and DASS are the most commonly used outcome measurement tools, but the survey found there is a lack of standardised outcome monitoring data in the CMO mental health sector. For further information on outcome measures see Section 8.1.1, and Appendix E.

Type 1 CMOs are more likely to be able to demonstrate the efficacy of their service provision with 60% reporting use of outcome measures, as per Figure 4.

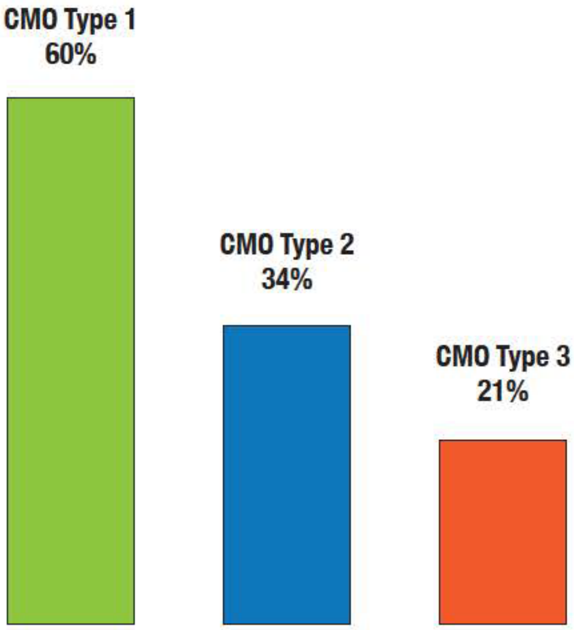


Fig. 4 The Proportion of CMOs Using Outcome Monitoring Toolsv

6.5 Other Australian and International Data Activities

There are various other activities, in Australia and internationally, occurring in relation to mental health and/ or CMO data systems development.

Western Australia

In 2000, Wood and Pennebaker developed Australia's first data management system for the NGO mental health sector in Western Australia and Victoria, and proposed its adoption nationally.

The system includes a classification of types of services, glossary of terms, a Standard Data Set with 35 elements, Data Dictionary, and reporting system.[52]

Wood and Pennebaker also list key principles for classifying services and terms. This provided an opportunity for the MDS Working Group to consider the principles in the development of the Comprehensive Data Set. The key principles are:

- Credible – supported by key stakeholders
- Internally valid – an accurate reflection of reality
- Mutually exclusive – no overlap between data groups
- Parsimonious – has the fewest categories accounting for the widest inclusions
- Functional – data must be observable, or meet a specific decision rule.[53]

Wood and Pennebaker acknowledge that this data set does not address all five questions posed by Leginski et al, but expect that it will lay the foundation for further development.[54] However to date it has not been implemented.

A well-constructed information system to provide purchasers, managers and providers of mental health services with management intelligence is essential for effective planning, resourcing, management and delivery of services to clients. Such a system was non-existent in Australian non-government community mental health sectors.[55]

---

[52] Wood, C., Pennebaker, Dr D. *The Non-government Mental Health Services Information Project Report* Centre for Mental Health Services Research Inc. Perth, Western Australia, October 2000, p11

[53] Wood, C., Pennebaker, Dr D., *The Non-government Mental Health Services Information Project Report,* Centre for Mental Health Services Research Inc. Perth, Western Australia, October 2000 p22

[54] Wood, C. Pennebaker, Dr D. *Non-government sector mental health data dictionary and standard data set,* Health Information Management Association of Australia undated, p12

[55] Wood, C. Pennebaker, Dr D. *Non-government sector mental health data dictionary and standard data set,* Health Information Management Association of Australia undated, p1

Australian Non-Profit Database

By the early 1990s, it had become clear that there existed no national database of non-profit organisations, no national statistics on the rate of volunteering in Australia, and very little information on the existing funding sources or levels. No one knew the size of the sector, nor had any way of assessing its importance to the Australian society and economy. Yet clearly such information is essential if the sector is to have a sense of itself as an entity, let alone be used in strategic policy and decision-making.

Accordingly, CACOM[56] began a process of sifting through the available ABS data sets, particularly that pertaining to industry data, to begin to get a sense of the size of the sector. Several small scale studies were undertaken to try and identify the kinds of categories under which non-profit organisations were registered at state and national levels, the adequacy of the existing registration data, and from this, estimates of the prevalence of different forms of non-profit organisations. Collaborative links were established with the Australian Bureau of Statistics in Canberra. The results of these exercises were published in some of the early CACOM working papers.

CACOM initiated and coordinated an Australia-wide study of the way governments ‘contract’ community organisations to provide care. This study was funded by the Law Foundation of NSW and resulted in a report, and a special issue of Third Sector Review, published in 1997 titled 'Contracting for Care'.

A second study was commissioned by the Fundraising Institute of Australia, and provided the first study of fundraising by government and non-profit organisations in Australia. However, the major effort of this research program centred on the Australian Non-Profit Data Project (ANDP). This project commenced in 1995 in collaboration with the Australian Bureau of Statistics and support from the Industry Commission, and aimed to collect and publish the first reliable and comprehensive statistics on Australia's non-profit sector, philanthropy and volunteering.

CACOM became the Australian participant in the John Hopkins University comparative Non-Profit Sector Project, which has to date collected comparable data on the non-profit sector in over 20 countries.

"Dimensions of Australia's Third Sector", the first technical publication from the Australian Non-Profit Data Project (ANDP) was published at the end of 2000. Three other technical publications are under preparation. In addition, the Australian national data has been incorporated into several international John Hopkins publications.

New Zealand

In 2005, New Zealand’s Te Pou National Centre of Mental Health and Workforce Development undertook a survey of mental health and addiction services, which

---

[56] Centre for Australian Community Organisations and Management www.business.uts.edu.au/cacom/index.html

share some similarities with the current situation in NSW. In relation to data management, New Zealand identified the following points:

- Information technology was mostly used for financial and payroll functions and documentation, and less for client monitoring
- There was inadequate continuity of care for clients as there was little sharing of information between NGOs and primary health practitioners
- Inadequate systems existed for national information collection and reporting
- Outcome measurement tools were not seen as a priority, and rarely used.[57]

In response, the New Zealand Ministry for Health developed a framework for ICT development in the mental health sector, with the following areas of priority:

- Shift focus from information collection to information use
- Minimise the cost of collecting information
- Increase opportunities for consumers to have input to clinical records
- Extend coverage of mental health data collection to primary health care sector
- Support Maori goals for *whanau ora* (wellbeing)
- Support information sharing among providers
- Use information for quality improvement
- Use information for research and development
- Fill data gaps and improve data quality.[58]

The New Zealand Ministry of Health bases its ICT development in the mental health sector on the principle that the quality of information needed regionally and nationally should be a by-product of the information collected locally. It considers that the quality of information is improved by providing a supportive environment to change individual and organisational behaviour in the collection and use of data.[59]

Over the last two years the role and scope of Te Pou's information program has evolved significantly. The program now has roles and responsibilities in a number of mental health information activities and initiatives and is also involved in:

- Promoting and supporting the development of systems and processes to capture and disseminate outcome information.

---

[57] National Centre of Mental Health and Workforce Development, *NgOIT Landscape Survey 2005,* New Zealand October 2006, p23-5

[58] New Zealand Ministry of Health, *National Mental Health Information Strategy 2005-10,* Wellington New Zealand, June 2005, pviii

[59] New Zealand Ministry of Health, National Mental Health Information Strategy 2005-10, Wellington New Zealand, June 2005, p1, 5

- The development of strategies that will support local services to manage and maintain ongoing training and skill development in the use of mental health information.
- Developing the Maori, Pacific peoples and NGO sectors' capacity to collect and use outcome measures.
- Building sector relationships to embed the use of outcome measures.[60]

Te Pou workforce development objectives are: to build a strong and enduring workforce to deliver mental health services to all people; and to develop a culture of continuous quality improvement in which information and knowledge is welcomed and used to enhance recovery and service development. Funded by the Ministry of Health, Te Pou's work is performed within four distinct, but interrelated, programs:

1. Workforce
2. Research
3. Information
4. Le Va – Pasifika

The 'Knowledge Exchange' supports the translation of knowledge into action by igniting a passion for learning, embracing information-sharing and research collaboration. Inspirational stories about mental health and addiction initiatives are shared to support service innovation and delivery towards best outcomes for service users.

The database of New Zealand mental health and addiction research provides information about recent and ongoing research projects. The database is an avenue for researchers to promote their work and a central place for people working in the sector to find out who is undertaking research, and what recent research is available.

New Zealand research which is published; unpublished or currently in progress that relates to mental health and addiction can be submitted to the database, including research that focuses on:

- assessment and diagnosis
- biological research
- epidemiology and risk factors
- clinical treatment
- practice research
- workforce training and development
- service systems research
- prevention and promotion.

---

[60] Te Pou National Centre of Mental Health Research, Information and Workforce Development, New Zealand www.tepou.co.nz/

United Kingdom

The United Kingdom is establishing a National Office for the Third Sector with the aim of strengthening the community by creating conditions for the third sector to thrive.

It has two key programs:

1. Change Up – promoting partnerships and support for capacity building
2. Future Builders – funds for capacity projects and specific development needs.[61]

One need identified for the sector is the improvement of information and communication technology, and recommends the following:

- Common awareness of funders and providers of the costs and benefits of ICT
- Affordable and reliable data systems
- User-friendly and relevant ICT advice
- Web-based information
- Phone help-line.[62]

> ***"The richest and most detailed information about a consumer is held at the local level for the purposes of delivering care and treatment. Only specific items of individualised consumer data are of interest to regional and national agencies and this information is usually presented in an aggregated format for planning and monitoring purposes."***[63]

---

[61] United Kingdom Audit Office, *Building the Capacity of the Third Sector,* 6 February 2009, p11

[62] United Kingdom Audit Office, *Building the Capacity of the Third Sector,* 6 February 2009, p41

[63] New Zealand Ministry of Health, *National Mental Health Information Strategy 2005-10*, Wellington, New Zealand June 2005, p3

7. Data Systems

In 1989, Leginski et al argued that good data systems are not simply an accumulation of data for its own sake, but should be a decision support system of data linkage that leads to action. The focus must be on the consumer and promote continuity of care. Consumers' confidentiality and privacy must be considered in how information is stored and provided to staff, funders, and other stakeholders.[64]

There are many critical aspects of best practice in relation to data management systems. Three key areas are:

1. Organisational understanding
2. Clear purpose for data collection
3. Balancing consumers' and organisations' needs.

7.1 Organisational Understanding

Organisations need to understand how technology can be applied, so that data management systems are integrated into effective work practices. Some best practice indicators are:

- There is a basic understanding of the meaning of information technology, i.e. organisational leaders have a basic working definition of information technology, and all staff members understand the basic hardware and software available to them.
- There is a basic understanding about when to use information technology, with leaders investigating how similar organisations are using technology and ensuring information on current technology is accessible to all parties.
- Board members, staff and clients support the use of information technology, with leaders developing an education plan for Board members, staff, and clients. [65]
- Organisational mechanisms are put in place to support the application of information technology.
- Clear policies and procedures, and guidelines about appropriate uses of information technology, security issues for storing confidential information and ethical collection and use of data are documented.
- There is an understanding of the sector approach to data collection and opportunities for data sharing.

---

[64] Wood, C., Pennebaker, Dr D., *The Non-government Mental Health Services Information Project Report,* Centre for Mental Health Services Research Inc. Perth Western Australia, October 2000, p65, 93-5

[65] Framework based on Whatcom Council of Nonprofits, *Best Practices for Executive Directors and Boards of Nonprofit Organizations*, pp22-24, WA USA www.wcnwebsite.org

Ticher et al, makes recommendations to senior managers and boards about how their roles can promote Information and Communication Technology (ICT) understanding and development, as follows:

- Senior managers – keep up to date by networking with colleagues, seek expert views from other fields, learn from the successes and failures in other organisations, and find a guru to help explore possibilities
- Board members – give the organisation time it needs to develop ICT capacity, support managers in their efforts to improve ICT, find resources to fund development, and recruit a board member with ICT expertise.[66]

“He uses statistics as a drunken man uses lamp-posts…

for support rather than illumination.” Andrew Lang 1844-1912

7.2 Clear Purpose for Data Collection

Organisations need to be clear about the purposes of data management systems. Broadly, the purpose is to enable community organisations to develop evidence-based practice, and share experiences about effective strategies and service models that promote consumer outcomes. Specifically, and regardless of the size or nature of the CMO, the primary purpose of a data management system is to standardise data collection across all programs, such as consumer details, service activities and measurable outcomes.

CMOs also need data management systems to demonstrate that they meet relevant service standards, efficiency and accountability arrangements and outcomes.[67]

The Australian Public Service Commission proposes that data systems should have the following characteristics:

- Client-focused design, including risks and needs
- Service quality, including standards and best practice
- Service accountability and sustainability
- Avenues for complaint and redress
- Information for service users
- Putting clients at the centre.[68]

---

[66] Ticher, P. et al., *Leading the Way to ICT success: Executive Summary, The report of the study of the issues affecting the use of ICT in the voluntary and community sectors,* United Kingdom, March 2002

[67] Australian Public Service Commission, *Policy Implementation through Devolved Government,* 2009, p26

[68] Australian Public Service Commission, *Policy Implementation through Devolved Government*, 2009 p44

Ideally, data management systems would be established from the start, in the context of an organisational culture of continuous quality improvement that directly benefits and improves consumer outcomes. There should be no service activities that are exceptions, and the system should be flexible enough to cover all situations.[69]

Adelman, et al considers that the key components of best practice data management systems are:

- Clarity about data ownership
- Enforcing data quality
- Integrating data across the organisation
- Standard and consistent terms and names of data collected.[70]

7.3 Balancing Consumers' and Organisations' Needs

It is essential to balance the needs of funders and service providers for information about organisational performance with the needs of consumers in respect of their privacy. The capacity of technology to capture information is extensive, so there also needs to be clarity about what information is actually required, and the risks associated with its use and dissemination.

Since there are important and justifiable reasons to collect data, the issue now becomes how to safeguard the confidentiality of the data and the privacy of the persons about whom (and from whom) the data is collected.[71]

The Australian National e-Health Transition Authority sought feedback on privacy issues, and found broad support for using information for research and improving public health and safety. However, there were concerns about information being used for direct marketing, or use by employers or insurers.[72]

The New Zealand Health Information Services has adopted a privacy code in data collection, storage and use, and includes:

1. Information collected must be lawful and necessary for purpose
2. Information should be collected directly from the individual, except where that person is unable to provide it, such as age or capacity
3. The process of collection should not intrude unreasonably on the personal affairs of the person
4. Information storage must protect against loss, unauthorized modification or disclosure, and misuse

---

[69] Adelman, S et al., *What is considered data management best practices?* Information Management Online, 8 January 2004

[70] Adelman, S et al, *What is considered data management best practices?* Information Management Online, 8 January 2004

[71] Ziglin, A. L., *Confidentiality and the Appropriate Uses Of Data*, 1995, http://www.mhsip.org/mhsiptest/documents/confid.htm

[72] National E-Health Transition Authority, *Privacy Blueprint for the Individual Electronic Health Record: Report on Feedback,* 2008, p4

5. Information must be accurate, up-to-date, complete, relevant, and not misleading
6. The agency retaining the information should not hold it longer than necessary for its purpose
7. The use and disclosure of the information must relate to the purpose for which it was collected
8. Unique identifiers should only be allocated it these are necessary for the agency to carry out its function
9. People have a right to access information held about them and request corrections.[73]

---

[73] Harding, E., *Privacy Impact Assessment and Commentary on the Mental Health Information Project for New Zealand Health Information Service,* February 1999, p36-60

8. Benefits of Data Systems

Mental health CMOs and governments are well aware of the benefits of comprehensive data management systems. Significant resources are being invested in developing relevant technology.

The Australian Institute of Health and Welfare (AIHW) identifies several key benefits of good data management systems. These are:

1. Increased efficiency and effectiveness in service delivery
2. Better case management of clients across programs and with other providers
3. Trend data is available for research and service development
4. Reduced frustration for clients and staff
5. Increased time for capacity building and professional development.[74]

This project explores some benefits in more detail, as follows:

- Enhancement of Recovery-Oriented Approaches
- Supporting organisational functions
- Promoting quality
- ICT Maintenance

'Data can be so much more than just a minimum data set sent to funding bodies.' MDS Working Group member

Enhancement of Recovery-Oriented Approaches

A data set can be used to enhance a recovery-oriented approach to service delivery, and also ensure the data collection; recording and monitoring process can be used to enhance consumer outcomes and experiences of the service user.

Some of the ways data could be used include the following:

- To create a baseline data set to assess the current status of the recovery orientation of a program or local system;

---

[74] Australian Institute for Health and Welfare, *Cutting the red tape: Preliminary paper detailing the problem of multiple entry and reporting by service providers* November 2006, p11-12

- To set specific benchmarks that target desired increments of progress toward achieving a recovery orientation;
- To measure change over time in the recovery orientation of the program or system;
- To compare the performances of provider agencies;
- To sensitize and educate mental health providers about important factors that facilitate or impede recovery; and
- As part of other targeted studies of mental health recovery, to develop a better understanding of how agency or system-level performance on key indicators relates to other recovery elements, processes, or outcomes.[75]

Supporting Organisational Functions

Governments and CMOs need reliable data for day-to-day operational functions, and to inform planning and decision-making. Therefore, organisations need to be clear about what data is collected and how it is used.

Standardised data collection is an important way of ensuring consistency in definition, allows comparison of data, avoids duplication, and contributes to reducing the costs of data systems development.[76]

Ideally, an organisation's data management system contains all the information needed to effectively manage their functions. Leginski et al developed five questions to guide the development of data management systems. These questions cover the essential information organisations require, and he proposes that data systems incorporate all aspects. This approach has been widely adopted in national and international data management development activities.

---

[75] National Association of State Mental Health Program Directors (NASMHPD), *Mental Health Recovery: What Helps and What Hinders?* A National Research Project for the Development of Recovery Facilitating System Performance Indicators, 2006 New York State Office of Mental Health

[76] Australian Institute of Health and Welfare, *A guide to data development*, 2007, p14

The following points show Leginski's five questions, and the type of data collected.

Leginski's Questions

1.	***Who receives…?***	**Demographic and clinical characteristics of clients**
2.	***What services…?***	**Details of mental health programs delivered - amount & type**
3.	***From whom…?***	**Service and workforce characteristics**
4.	***At what cost…?***	**Mental health service expenditure**
5.	***With what effect?***	**Client outcome data.**[77]

Using Leginski's questions, the United States Centre for Mental Health Services developed an alternate framework for the types of information it required:

- Information collection
    - Descriptive information – What are we doing?
    - Evaluative information – How well are we doing?
- Information application
    - Prescriptive information – What should we be doing?
    - Corrective information – Does what we are doing match what we should be doing?[78]

Organisations also need data management systems to be flexible to the levels of risk associated with the organisation's functions.

For example, there are greater risks related to some individuals with mental health problems, such as people at risk of harm to themselves or others, and service types such as CMOs providing whole-of-life services e.g. high level supported accommodation. With higher levels of risk, it is reasonable to expect higher levels of accountability from CMOs. However, there needs be considerable thought to identifying what data is collected, as increased requirements for accountability and transparency encourages risk avoidance and consistency in data collection, but may have unintended consequences, such as limiting high performance and innovative approaches to service delivery.

Other aspects of data systems that enhance organisational performance are:

- Information and Communication Technology (ICT) planning is included in all other types of planning throughout the organisation.

---

[77] Wood, C., Pennebaker, Dr D., *The Non-government Mental Health Services Information Project Report,* Centre for Mental Health Services Research Inc. Perth Western Australia, October 2000 p18

[78] Department of Health and Ageing, *National Mental Health Information Priorities,* 2nd Edition June 2005, p11

- An information technology plan is established that outlines what the organisation does and how technology supports those functions.
- The inclusion of culturally important concepts, such as connectedness and community, including for people who are from Aboriginal or Torres Strait Islander backgrounds, or cultural and linguistically diverse communities.
- To ensure mandatory fields, registered system users, capacity to track and produce reports, be secure and cost-effective are included.

Promoting Quality

Comprehensive data systems promote the quality of information available to organisations, increasing opportunities for effective progress monitoring and evaluation, and the capacity for flexible and timely responses to changes in client and organisational needs. Ideally, data systems record the time and resources that are invested in operational functions, and track the outputs and outcomes achieved. This enables the organisation to review its performance against recognised best practice and standards.

Ultimately, the organisation can be well-informed and confident about the effectiveness of all its activities, and transparent in its accountability to clients, stakeholders, the community and funders.[79]

ICT is evolving in the CMO sector, therefore systems development must support learning from experience, testing and evaluation, engagement with stakeholders, and sharing performance information.[80]

Some specific aspects of comprehensive data systems that promote high quality services include:

- All financial costs and benefits are considered when making information technology decisions, including staff training, consultants, hardware, software, maintenance and upgrades. Plans for ICT development could reflect approximately 2-3% of the organisation’s annual budget.
- Indirect costs are considered when making ICT decisions. These may include staff time to learn necessary skills, back-fill of staff and office space.
- The exploration of ways that ICT can solve problems and add value to the organisation. This could include cost-saving strategies, linking information, and developing reports on specific areas of interest, such as risk and best practice.
- Exploring alternatives, such as out-sourcing expensive or complicated aspects of the ICT system, or collaborating with similar CMOs that are looking for technology solutions to common problems.

---

[79] Harding, E., *Privacy Impact Assessment and Commentary on the Mental Health Information Project for New Zealand Health Information Service,* February 1999, p42

[80] Australian Public Service Commission, *Policy Implementation through Devolved Government,* 2009, p35

ICT Maintenance

An essential decision for all organisations is how to maintain quality data systems, especially in relation to using the available resources in the most effective way, rather than trying to do too much. This means choosing equipment or upgrades that meet the organisation's needs. An organisation should not need to wait any longer than six months to see the benefits of ICT changes.[81]

Organisations have several options, including contracting ICT upgrades and maintenance to external companies, or designating specific positions. An alternate approach is to identify a staff member(s) who is interested in information technology and willing to act as a part-time information technology specialist, particularly if the organisation is not large enough to have a designated position.

In the United Kingdom, an ICT support organisation recommends that a rule-of-thumb for ICT staffing is one full-time IT support person for 50 staff, which is equivalent to one day per week for each ten staff members. In all cases, the organisation may also need to engage external expert support at times.[82] This external support could take the form of a circuit rider model.

A circuit rider program operates in the United Kingdom and United States to support small CMOs to develop and make optimal use of ICT systems. Circuit riders are people with specific ICT expertise, and support a caseload of CMOs that are too small to be able to justify the cost of employing a staff member for this role. The aim is for CMOs to become self-reliant.[83]

---

[81] Adelman, S et al., *What is considered data management best practices?* Information Management Online, 8 January 2004

[82] Lasa Information Systems, Staff responsibility for IT support, www.ictknowledgebase.org.uk

[83] Lasa Information Systems, *So what is a circuit rider?* Lasa Circuit Riders 2.0 www.ictknowledgebase.org.uk

9. Conclusion

The development of an evidence-based, recovery-oriented CMO service system that enhances knowledge creation and management, improves relationships with consumers and carers and builds on quality performance systems is the focus of the MHCC Data Management Strategy.

This report provides information regarding an industry-developed comprehensive data set and a proposed minimum data set, while promoting the better use of data collection by CMOs. The report hopes to achieve the commitment and engagement of NSW Health and others at state and national levels in the development of better systems for understanding of CMO data collection and use.

The Data Management Strategy is building on previous MHCC activities to enhance the capacity of the CMO sector. Through the work of the CMO members on the DMS Reference Group and the three working groups - MDS; Systems and Data Dictionary; NSW CMOs working in mental health are a step closer towards being able to access and understand CMO data. The undertaking of Phase 2 of the Data Management Strategy with NSW CMOs, in partnership with NSW Health is the next step. MHCC looks forward to the findings of the AIHW Scoping Study Report with strategies to reduce the burden on CMOs and improve data reporting.

The recommendations that have arisen from the findings in this report are proposed as a way forward to promote best practice data management systems for CMOs working in mental health in NSW.

It is recommended that:

1. MHCC work with NSW Health and other funding agencies to reach agreement on a core Minimum Data Set, and the collection and use of CMO data.

2. MHCC commence discussions with government agencies to seek cross-government collaboration about the content and process of CMO reporting by state and federal governments.

3. MHCC commence Phase 2 of the Data Management Strategy, including a scoping study to determine the technology infrastructure requirements of CMOs working in mental health in NSW, and development of a business plan to enhance CMOs’ technology capacity.

4. MHCC Learning and Development Unit undertake (i) training of CMO staff in the use of data sets and data systems (ii) integration of outcome measurement education across all relevant CMO training packages and (iii) develop an Outcome Measurement User Manual for CMOs working in mental health in NSW.

5. MHCC investigate corporate licensing options to enable access to a cost-effective data management system for small and medium mental health CMOs.

6. MHCC, the CMO sector, NSW Health and other government agencies commence discussions with regard to development of a mechanism whereby CMO data can be accessed by a range of stakeholders including CMOs, peak

bodies, government agencies and research institutes based on a level of authority access structure. This would enable collection of de-identified sector data for quality improvement, benchmarking, and research purposes.

7. MHCC commence discussions with Community Mental Health Australia regarding the establishment of a national mental health CMO clearinghouse. This organisation would collect best practice from mental health CMOs, which would be publicly available to consumers, carers, MHCC members, the sector and funding bodies.

Better data will improve understanding of how Not-For-Profits enhance community wellbeing and facilitate macro level analysis of policy effectiveness.[84]

---

[84] Australian Government Productivity Commission, *Contribution of the Not-For-Profit Sector,* Research Report, Canberra, January 2010, p LV1

Appendix A

Data Management Strategy Reference Group Members

Membership of the Reference Group changed over the project’s length due to a number of reasons including:

- The difficulty for smaller CMOs to commit time and resources to a large project
- Changes in CMO staff who were members
- A number of larger CMOs commenced developing their own database systems.

The DMS Reference Group members are thanked for their advice, guidance and active participation with the DMS Project. The staff time and in-kind support generously provided by CEOs and Senior Managers to the Data Management Strategy is appreciated.

Membership of the DMS Reference Group has included at some time during this project the following individuals and organisations:

- Jenna Bateman, MHCC
- Dodie Bennett, PRA
- Ian Bond, MHCC (Minutes)
- Mark Buckingham, Kedesh Rehabilitation Services
- Joyce Cheung, One Step at a Time Counselling
- Aidan Conway, The Richmond Fellowship of NSW
- Julia Davis, Community Restorative Centre
- Catherine Deegan, Adults Surviving Child Abuse
- Pedro Diaz, Aftercare
- Tracey Fairley, PRA
- Marie Fox, Aftercare
- Jonathan Harms, ARAFMI
- Judi Higgin, New Horizons
- Dr Cathy Kezelman, Adults Surviving Child Abuse
- Jo Khoo, NADA
- Michelle Kightley, Schizophrenia Fellowship NSW
- Stephen Kincaid, New Horizons
- Fay Kohlhagen, GROW
- Gerri Koelma, The Benevolent Society

- Paul Langdon, The Richmond Fellowship of NSW
- Kerry Lockhart, St John of God Health Care
- John Malone, Aftercare
- Peta Maskell, Break Thru People Solutions
- Stephanie McGrath, Break Thru People Solutions
- Ron McCullagh, GROW NSW
- Janet Meagher, PRA
- Angela Milce, Carers Assist, Schizophrenia Fellowship NSW
- Julie Millard, MHCC (Chair/Minutes)
- Phil Nadin, PRA
- Mark Orr, PRA
- Dale Owens, Justice Health
- Arthur Papakotsias, Neami
- Edwina Pickering, Consultant to MHCC
- Jonine Penrose-Wall, Consultant to MHCC
- Elita Purcil, One Step at a Time Counselling
- Dr Grenville Rose, Aftercare
- Kris Sargeant, RFNSW
- Julie Taylor, Exodus Foundation

Appendix B

Membership - MDS, Systems & Data Dictionary Working Groups

The members of the three working groups are thanked for their enthusiasm, constancy, active participation and commitment to the Data Management Strategy, without which there would be no Comprehensive Data Set with rationales, proposed Minimum Data Set, database-essential criteria matrix or review of eleven database systems.

It is both commendable and validating of the process that a number of members actively participated in two (and three) working groups.

1. MDS Working Group

The membership of the Data Management Strategy MDS Working Group remained predominately constant throughout the project from April 2009 till April 2010 with only minor changes to the initial contingent of 16 individuals representing 12 CMOs.

The working group met on 20 occasions, including for one whole day with each member undertaking tasks outside of the meeting parameters.

The members of the MDS Working Group have been:

- Dodie Bennett, PRA
- Ian Bond, MHCC (minutes)
- Mario Fioretti, PRA
- Paul Francis, The Benevolent Society
- Shane Jakupec, Neami
- Michelle Kightley, Schizophrenia Fellowship NSW
- Angela Milce, Carers Assist, Schizophrenia Fellowship NSW
- Stephanie McGrath, Break Thru People Solutions
- Julie Millard, MHCC (Chair)
- Dr Grenville Rose, Aftercare
- Malcolm Scott, Neami
- Ann Wilson Whatley, Mental Health Carers ARAFMI NSW I

2. Systems Working Group

The Systems Working Group members of the Data Management Strategy ensured due diligence in the creation of the database-essential criteria matrix and the review of 11 commercially developed database systems that were considered appropriate for use by large, medium and small mental health CMOs.

The Working Group commenced in April 2009 and met 11 times over a period of seven months, with each member undertaking tasks outside of the meeting parameters.

The members of the Systems Working Group have been:

- Ian Bond, MHCC (Minutes)
- Tracey Fairley, PRA
- Judi Higgin, New Horizons
- Shane Jakupec, Neami
- Paul Langdon, The Richmond Fellowship of NSW
- Julie Millard, MHCC (Chair)
- Dr Grenville Rose, Aftercare

3. Data Dictionary Working Group

The Data Dictionary Working Group commenced in July 2009 till November 2009 with the assistance of a Consultant, to develop a draft CMO Mental Health Data Dictionary that was to be user-friendly and specific to the needs of CMOs working in mental health.

The working group met on 5 occasions with each member undertaking numerous tasks with METeOR outside of the meeting parameters. In December 2009 the working group was amalgamated with the MDS Working Group. Members of the working group were:

- Dodie Bennett, PRA
- Ian Bond, MHCC (Minutes)
- Mario Fioretti, PRA
- Shane Jakupec, Neami
- Julie Millard, MHCC (Chair)
- Jonine Penrose-Wall, Consultant to MHCC
- Dr Grenville Rose, Aftercare
- Malcolm Scott, Neami

Appendix C

Biographies of CMO Members on Working Groups

Dodie Bennett

Dodie started work in PRA Supported Business services in 2003. She felt this was the ideal opportunity to give something back to people that she empathised with. Dodie then moved to a new position managing a team of peer support workers, and implementing the rollout for PRA of an Outcome Tool, the CANSAS.

Dodie is passionate about the introduction of an outcome tool as it was a chance to ensure every consumer received individual, holistic support. The data provides PRA with a chance to ensure evidence-based practice is in use, and that consumers have a voice in service provision and continuous improvement. Dodie is currently studying for a degree in Social Work, and plans to continue working in mental health.

Ian Bond

Ian is the IT Administrator for MHCC. He has worked in community mental health, disability employment and with other mental health non-government organisations for the past 25 years. Ian has experience in database development and programming for both NSW Health and disability employment where he interfaced the Centrelink database with other databases.

Mario Fioretti

Mario is an experienced Technical Writer and Quality Practitioner in the Service, Manufacturing and Telecommunications Industries and holds an Engineering degree. He has been with PRA since 2005 working as Documentation Officer developing data management systems for all of PRA services and programs.

As of 2010 Mario has been appointed as the Information Systems Manager for PRA Database Project and other information systems.

Paul Francis

Paul is the Project Officer, Social Policy and Research department, Benevolent Society. His present role is carrying out long-term longitudinal evaluations of the Benevolent Society’s major projects with Community Care, Brighter Futures and PHaMS program.

Paul’s background is an electronics engineer but in the past 15 years his interest in social issues has led to employment as the National Quality Manager for Mission Employment, achieving certification for Employment and Community Services in Queensland, and a Bachelor of Social Science with UNSW. He has been with the Benevolent Society for nearly 7 years.

Judi Higgin

Judi Higgin is the General Manager for New Horizons, responsible for all of the mental health and disability services. Judi has worked in the community sector for 27 years, has a passion for social justice and has held a number of management and leadership roles. Judi has a Bachelor of Social Science and a Diploma of Business (Front Line Management) and is currently studying for her Executive MBA.

Shane Jakupec

Shane has been working in the mental health sector since 2000. He has experience in a number of areas that includes service and contract management, recruiting and managing volunteers and delivering accredited mental health training with MHCC. Shane currently works as the Service Manager at Neami Hurstville, joining Neami in late 2006. Shane holds a BA Theology, Ad Dip Community Management and a Cert IV in Training and Assessment.

Michelle Kightley

Michelle Kightley is an Occupational Therapist who graduated with Honours, University of Sydney in 2008. Her Honours thesis examined the feasibility of utilising pre-collected MH-OAT data to examine the quality and effectiveness of a non-government organisation, Pioneer Clubhouse. This study is awaiting publication in *Australasian Psychiatry*.

The Schizophrenia Fellowship of NSW (SFNSW) employed Michelle as a Project Officer in 2009. Her role was to identify appropriate outcome measurement instruments and processes for the recovery and carer programs of the SFNSW, examine the future process of implementation and how the data collected using the chosen measurement instruments can be used to improve the quality and effectiveness of SFNSW programs. Michelle is working as an Occupational Therapist at Macquarie Hospital.

Stephanie McGrath

Stephanie McGrath is an Employment Support Consultant in the Disability Employment Network program with Break Thru People Solutions. This role involves assessment of both eligibility for the program and then support needs for successful participation in this employment-outcome driven program. It is a generalist program available to people with a broad range of barriers to employment including physical and intellectual disabilities, mental health issues, acquired brain injury and combinations thereof.

Break Thru People Solutions has been providing services to people with disabilities to achieve employment for 15 years starting in Western Sydney and now recognized nationally as an industry leader.

Angela Milce

Angela changed career direction to the field of mental health in 2002. Prior to this she was involved in scientific research in the area of physical chemistry. Angela has been involved with the family and carer program since then, commencing with the demonstration project managed by the Schizophrenia Fellowship of NSW Inc. During this time, she has received training and education in all aspects of working with mental health carers including mental health first aid, Well Ways and various Statements of Attainment from Certificate IV in Mental Health.

Angela is now Manager of Carer Assist, a service of the Fellowship, operating within three Area Health Services (Greater Southern, Hunter New England and Sydney South West) in NSW as the NSW Family and Carer Mental Health Program.

Julie Millard

Julie Millard has worked in the mental health and disability sectors for the past 25 years engaging with a wide range of stakeholders and community-based agencies. Since 2008 Julie has worked as a Consultant and draws on her diverse professional experience in mental health nursing, community development, project management and from establishing mental health supported accommodation services in rural and regional NSW for the non-government sector. Julie has written policies, guidelines and successful funding submissions to provide new community service programs, managed projects to support people living with a mental illness including addressing physical health care needs, and developed and delivered training and education for CMOs, university, hospitals, carer and community groups.

Julie is the Coordinator of the MHCC Data Management Strategy Phase 1.

Dr Grenville Rose

Dr Grenville Rose has worked as a researcher since 1992. Grenville’s background includes mainly quantitative research in: clinical and cognitive psychology, the development of human food preferences, community pharmacy and commercial market research in the food and beverage industry.

Grenville has been working for Aftercare as Coordinator of Evaluation and Innovation since 2007. While working at Aftercare Grenville has conducted and designed projects on consumer satisfaction and attitudes towards drug and alcohol comorbidity in two NSW-based mental health NGOs. Grenville’s research with Aftercare has involved collaborations with New Horizons, the University of Wollongong, the University of NSW, the National Centre in HIV Social Research, the University of Queensland, and the Mental Health Coordinating Council.

Malcolm Scott

Malcolm has over 10 years experience in disability and mental health having worked across both DADHC and NSW Health funded services. He has a BSc from Macquarie University with a major in psychology, with interests including working with people with multiple and complex needs including acquired brain injury and intellectual disability, mental health and alcohol and other drug issues.

In his role with the Community Integration Program at the Royal Rehabilitation Centre Sydney he began as Community Support Worker and then progressed to a Team Leader. Since joining Neami in 2006 Malcolm began as a Service Manager East Sydney and progressed to Regional Manager Northern NSW in January 2009. He is currently overseeing six sites including the new Assertive Outreach and Support Team being established for the City of Sydney Local Government Area.

Ann Wilson Whatley

Ann Wilson Whatley works for Mental Health Carers ARAFMI NSW, currently as the Promotions and Development Officer. In 2009 ARAFMI was appointed as the peak body in NSW representing families and carers of people living with a mental illness. Since completing a Bachelor of Science with Distinction (Psychology) in 2002 Ann has worked in the mental health sector, firstly with consumers using psychosocial rehabilitation and Recovery models of intervention, and in 2007 joined ARAFMI in the role of Information Officer.

Ann has had experience as a mental health carer, and has a background in information technology having trained and worked for many years on IBM mainframe computers as a systems analyst and project manager.

Appendix D

Drug and Alcohol NGO Sector

Information from the Drug and Alcohol and Mental Health Information Management Project background paper follows regarding development of the Minimum Data Sets for Drug and Alcohol services and also the development and object of the Information Management Project.

Development of the National Minimum Data Set

In 1995, the Alcohol and Drug Council of Australia (ADCA), as the national peak body for the non-government drug and alcohol sector held a forum, which looked at the barriers between research and service delivery. One of the recommendations from the forum was the development of a national minimum data set for alcohol and drug treatment services.

A feasibility study was subsequently funded that found some data was collected by agencies but they were not recorded or were reported inconsistently. This led to Phase 2 – the development of the Alcohol and Other Drug Treatment Services National Minimum Data Set (AODTS NMDS), overseen by the then Commonwealth Department of Health and Aged Care. All states and territories agreed to the national collection of a defined set of treatment data elements with data collection commencing in July 2000. This data set was a subset of the agreed NSW Minimum Data Set for Drug and Alcohol Treatment Services (NSW MDS DATS).

Non-government service providers have the option of using an on-line data collection system operated by NADA to collect the NSW MDS DATS. The development of the on-line data collection system for NGOS was funded by the NSW Health Department in 2000. This allows agencies to log in to the database from any computer to enter the data, rather than collecting it on a single computer. On behalf of the agencies, NADA creates the relevant reports and forwards them back to the agency, the Area Health Service Drug and Alcohol Data Coordinators and, where relevant, the Commonwealth Department of Health and Ageing.

Other Data Collection in the NGO Drug and Alcohol Sector

The type of consumer and service data collected across the NGO drug and alcohol sector varies, as does how it is collected and stored, and how that information is used. Brief scoping exercises carried out by NADA in 2006 and 2007 identified that some organisations collect only required data items (such as MDS), some collect data in addition to those required for compliance purposes but do not appear to make use of the data, while others did use some of the data for their own planning purposes.

The variation in data management practices across the sector may be attributed to a multitude of factors, including the range and level of intensity of service types provided, the resources available to collect, store and analyse data, the capacity of staff to identify and use relevant tools, and the levels of understanding as to how the data can support organisation planning and advocacy.

In late 2008, NADA was provided a grant by NSW Health to undertake an information management project over a four-year period. This project will support the sector in the provision of quality care and planning for clients with drug and alcohol and mental health issues, and build the capacity of agencies to assess and measure outcomes for clients with drug and alcohol and mental health issues.

The identification of relevant tools, measures and systems was an early part of the NGO Drug and Alcohol and Mental Health Information Management Project. Consultation with service providers and those with expertise in related research and information management informed the selection of measures. At the time of writing this report, NADA was piloting the Treatment Outcomes Data Collection System with a small group of its member agencies before rollout to the non-government drug and alcohol sector in 2011.

Appendix E

Additional Data Management Strategy Methodology Information

Key Components

A. Reference Group

The DMS Reference Group was formed to provide advice, guidance and assistance to the project. All MHCC members were invited to participate, as all have an interest in the outcomes of the project. Its role was as follows:

- Ensure MHCC's Data Management Strategy meets the needs of the NSW CMO sector.
- Ensure the Data Management Strategy aligns with relevant federal and state data requirements and data collection.
- Assist the Strategy by providing a forum for discussion, problem-solving and brainstorming.
- Provide comment on reports and other material generated through the Data Management Strategy.
- Provide advice and information on technical requirements for implementing the Strategy.
- Provide advice and assistance in developing initiatives &/or resources when required and able.
- Promote the Data Management Strategy to the CMO sector where able and appropriate.

B. Working Groups

1. Minimum Data Set Working Group

The Minimum Data Set Working Group was formed to develop a specific data set for mental health CMOs in NSW, and a booklet explaining the rationale for new and excluded items (with reference to the National Health Minimum Data Set). The working group had the following tasks:

- Evaluate existing data collection systems required by funding bodies, and those actually used by CMOs.
- Evaluate CMOs' compliance with those systems, and identify issues arising.
- Consult key stakeholders about draft data collection sets.
- Develop a data collection set that incorporates existing systems, and demonstrates best practice.

2. Systems Working Group

The Systems Working Group was formed to produce a report with recommendations about database systems for both large and small mental health CMOs in NSW.

The group was to examine systems that reflect best practice and quality performance management, and are affordable, innovative, accessible and a flexible implementation model.

3. Data Dictionary Working Group

The Data Dictionary Working Group was formed to develop a Mental Health CMO Minimum Data Set Data Dictionary that is user-friendly and specific to the needs of mental health CMOs. It aimed to complement the work of the Minimum Data Set Working Group by providing definitions for the data set.

C. Consultations

The MHCC DMS project undertook specific consultation with a number of individuals and organisations that had significant interest in this project e.g. NSW Health and NADA, or who could provide guidance and advice.

NSW Health

NSW Health funds the DMS under the Infrastructure Grants Program, a broad sector capacity building program administered by MHCC. In April 2009, MHCC provided a briefing paper to NSW Health on the Data Management Strategy Project, including its purpose, planned activities, and connections with MHCC's other sector development projects, and achievements to date.

In May 2009, MHDAO commenced a four-year project to improve information management in NGOs funded by NSW Health, by targeting drug and alcohol treatment services. MHCC is a member of this working group in conjunction with NADA and is a representative at the NSW Mental Health Drug and Alcohol Information Sub-committee (MHDAIS). An additional consultation meeting occurred with an InforMH staff member in January 2010 to discuss the DMS Project.

NADA

NADA is the peak body for drug and alcohol NGOs, including those focusing on comorbidity. NADA has taken significant steps forward in developing data management systems for members. The DMS Project Coordinator represented MHCC as a member of the NADA NGO Drug & Alcohol and Mental Health Information Management Project Advisory Group meetings. Additional meetings took place between NADA and MHCC to strengthen relationships and consult regarding data management.

CEOs of CMOs

Ongoing consultation with CEOs and staff of CMOs in NSW occurred throughout the project to gather information about current data collection and usage, and to inform and promote the DMS project.

Australian Institute of Health and Welfare

Consultation with the Mental Health Services Unit of AIHW occurred at a meeting on 30 November 2009, to seek advice on the Data Management Strategy CDS and proposed MDS. Further consultation occurred in early February 2010 through the mental health NGO scoping study being undertaken by the AIHW, which is complementary to the work being undertaken by MHCC in NSW.

Other Individuals and Organisations

Throughout the projects' breadth a number of individuals were consulted in regard to specialty items. The following list is a small selection of individuals that attended meetings or teleconferences:

- Ann White, Executive Officer and John Gherardi, Board President - Western Australia Association for Mental Health, August 2009
- Dr Ilse Blignault and Associate Professor Melissa Haswell–Muru Marri Indigenous Health Unit School of Public Health and Community Medicine University of NSW, November 2009
- Michelle Swallow, Executive Officer – Mental Health Council of Tasmania
- Glenn Williams, Mental Health Coordinator–Aboriginal Health & Medical Research Council
- Gerry Naughtin, Executive Officer – Mind Australia

D. Dissemination and Promotion of Information

CEO Forum

In August 2009, MHCC hosted a CEO Forum in Redfern for the mental health CMO sector, to explore a range of issues affecting the state. Information about the DMS Project was presented, and discussion facilitated to seek feedback on key aspects, including standardised documentation, implementation of outcome monitoring, evaluation processes and data agreements. Three working group members, Stephanie McGrath, Dr Grenville Rose and Shane Jakupec also discussed their experiences of being involved in the project.

MHCC/ NADA Conference

MHCC and NADA co-hosted the *Outside In: Community Responses to Complex and Diverse Needs* Conference in Sydney in May 2009. A collaborative NADA/ MHCC interactive workshop *"Do you do data, darling?" A 'Great Debate'*: was facilitated by Jo Khoo Program Manager NADA, Julie Millard DMS Coordinator MHCC and Jonine Penrose-Wall Consultant to MHCC. The workshop was an opportunity to:

- Introduce each sector to one another
- Show the different data development journeys of the two sectors
- Showcase the capacity and knowledge available within each sectors data collections or envisaged data collections
- Present information about the DMS Project
- Seek feedback on specific data issues.

VICSERV Conference

A paper on the DMS project titled: *The Data Management Strategy for NGOs working in Mental Health in NSW: Facing complex decisions about the nature and use of electronic data systems* was presented in Melbourne in April 2010 at the VICSERV International Mental Health Conference - *Unfinished Business: Pathways to Social Inclusion*.

Information Dissemination

Information about the DMS Project was made available and updated on MHCC website, through the members' *FYI e-Fax* newsletter and the *View from the Peak*, the quarterly MHCC published newsletter.

The draft DMS Report was distributed for comment to the following individuals and organisations:

- DMS Reference Group Members
- MDS/DD Working Group Members
- NSW Consumer Advisory Group
- Chronic and Continuing Care, Rehabilitation and Recovery Working Group (CCCRRWG) Members, NSW Health
- InforMH Staff, NSW Health
- Mental Health Drug and Alcohol Information Subcommittee Members, NSW Health

- Mental Health Services Unit Staff, AIHW

E. Other information Sources

Literature Search

A literature search was undertaken to identify local, national and international information to inform the DMS project. Documents were sourced from the Internet and hard copy media, including government and research reports, journal articles, and other unpublished reports and papers. A full reference list is included at Appendix P.

MHCC Sector Mapping Project Data

During 2008-09, MHCC undertook the Sector Mapping Project involving a survey of CMOs providing mental health services in NSW. The DMS project has accessed some of the data results that are specific to the data management and information needs of the sector. These results are shown and acknowledged throughout this report.

F. Project Evaluation

MHCC planned an evaluation of the outcomes of the DSM project, including achievement of objectives. Table 10 shows the key performance indicators identified at the commencement of the project and the outcomes.

Table 10: Achievement of Performance Indicators

Performance Indicators and (Outcome)
Project management
• Contract with suitable qualified consultant for project management for 2 days per week ***(Achieved)***
• Relevant project reports, government frameworks and data dictionaries reviewed ***(Achieved)***
• Project Background paper developed for MHCC members and key stakeholders

Performance Indicators and (Outcome)

(Achieved)

- DMS Reference Group established and maintained, incl. Terms of Reference developed and reviewed and quarterly meeting schedule formalized ***(Achieved)***
    - Distribution of background paper to Reference Group members ***(Achieved)***
    - Reference Group members informed of project progress ***(Achieved)***
- Synopsis of project on MHCC website for public reference ***(Achieved)***
- CEO and MHCC Board informed through monthly Board reports ***(Achieved)***
- Four IGP Reports completed ***(Achieved)***
- First draft of DMS Recommendation Report ***(Achieved)***
- DMS Recommendation Report finalised and presented to MHCC CEO and Board ***(Achieved)***

Working groups

- MDS Working Group established and maintained, incl. Terms of Reference developed and reviewed and fortnightly meeting schedule formalized ***(Achieved)***
    - Comprehensive Data Sets identified and developed for Consumers ***(Achieved)***
    - Proposed Minimum Data Set determined for mental health CMOs in NSW ***(Achieved)***
- Systems Working Group established and maintained, incl. Terms of Reference developed and reviewed and fortnightly meeting schedule formalised ***(Achieved)***
    - Organised database demonstrations for review by working group ***(Achieved)***
    - Identification of diverse funding sources for NSW CMOs ***(Achieved)***

Performance Indicators and (Outcome)

  - Determined size and number of mental health CMOs
    (Achieved)
  - Developed and completed Database Essential Criteria Matrix
    (Achieved)
  - Identification of relevant databases, based on best practice and quality management, for small, medium and large mental health CMOs
    (Achieved)
  - Determination of proposal and suitability for MHCC to hold a corporate database software license for smaller CMOs
    (Achieved)
  - Relevant preliminary data regarding data systems, usage and needs acquired for working groups
    (Achieved)

- Data Dictionary Working Group established and maintained, incl. Terms of Reference developed and reviewed and meeting schedule formalized
  (Achieved)
  - Comprehensive Data Dictionary developed that includes information on the two data sets, i.e. Consumer and Carer
    (POSTPONED)
  - Social connectedness outcome measures reviewed for the MDS Working Group
    (Achieved)
  - Reviewed MDS of 22 funding sources against 2 x Comprehensive Data Sets
    (Achieved)

Other Consultation

- Meetings attended at NSW Health Information Strategy Committee; Mental Health and Drug and Alcohol Information Sub-Committee
  (Achieved)
- Briefing paper to MHDAO developed seeking additional funding for CMO sector
  (Achieved)
- Meetings attended at NADA NGO Drug & Alcohol and Mental Health Information ***(Achieved)***Management Project Advisory Group
- Meetings attended quarterly with relevant CMO mental health sector data and information provided
  (Achieved)

Performance Indicators and (Outcome)
• Facilitated and co-presented Data Symposium at MHCC/NADA Conference ***(Achieved)*** • Presented at MHCC CEO Forum ***(Achieved)*** • Presented at VICSERV Conference April 2010 ***(Achieved)***

MHCC will commence Phase 2 of the DMS project during 2010 and undertake a further evaluation of the uptake of this report's recommendations by relevant parties.

Issues Arising

Some procedural issues arose during this project. This section outlines these issues and strategies undertaken to address them.

- Timeframes - Overall, the Data Management Strategy project occurred as planned. There were some minor delays relating to the completion of the report due to the project workload being greater than 2 days a week, working group membership changes as a result of staff leaving a CMO or being reassigned, and a delay in the receipt of a document, which were overcome by increased MDS working group meetings and assigning of specific tasks to members.
- Resource availability – MHCC allocated administration support for the working groups however this did not always occur due to other workload pressures. The DMS Project Coordinator undertook additional hours and addressed this issue.

Risks Identified at Project Commencement

- Resources to deliver the project are not available or restrained.
- Project becomes larger than anticipated and therefore affects the focus &/or timeframe of the project.
- Personnel become either unavailable or unable to complete tasks.
- CMOs may be cautious about providing information on own data management practices.

Strategies to Minimise Risks

- Working groups' membership were large and diverse and therefore sustainable if some members were unable to continue.
- Key personnel contracted to deliver specified task.
- Submissions to engage dedicated administrative support for the project.
- Monthly reports to CEO and Board.
- Frequent meetings with CEO to update on progress and discuss issues arising.
- Emphasis on benefits of collaboration for CMO sector development.
- Participation in working groups was voluntary.

Challenges Arising during the Course of the DMS Project

- Maintaining consumer/ carer focus, and development of user-friendly products.

- Ensuring a representative view of both large and smaller CMOs on state-wide scope of project.
- Difficulty of smaller CMOs to commit time and resources to a large project.
- Collecting information about IT practices of more than 170 CMOs who work in mental health in NSW.
- Administrative support approved but insufficient for project.
- Significant delay in receipt of document that was required by working groups.
- Scope of project increased from focus on NSW CMO Minimum Data Set to one that might have national importance.
- Significant time investment required of working group members.
- Steep learning curve of complex information for members of working groups.
- Estimated time greater than anticipated for project management.
- Encouraging broad participation had to be balanced against the traditional role of a Reference Group.
- MHCC moved offices during the course of the project.

Strengths of the DMS Project

The DMS Project achieved its objectives, as follows:

- Development of a CMO-driven Comprehensive Data Set that is consumer-focused, recognises the role of carers, has rationales for inclusion of data elements and is compatible with the national data dictionaries
- Development of a proposed Minimum Data Set for the sector
- Potential for national application for products of the project
- Closer collaboration between CMOs on data system development
- Members of working groups became advocates of the project
- Constructive liaisons with other health organisations
- Members of working groups expanded knowledge and enthusiasm about data management systems
- Recognition of the value of people’s commitment and time and setting up environments that were conducive to constructive output, including catering
- Project occurred at a time when there is global interest and action on developing data management systems for CMO sector
- Availability of previous and current MHCC projects that identified needs and explored specific issues related to this project.

Government has a responsibility for "ensuring the enablers of change are properly resourced, not only in funding terms but also with skills of the right calibre."[85]

---

[85] Gershon, Sir P., *Review of the Australia Government's use of Information and Communication Technology (ICT), Publication Summary,* October 2008, p5

Appendix F

Key Documents in Mental Health

Year	Key Milestones
1991	• Australian Mental Health Statement of Rights and Responsibilities
1992	• United Declaration Principles on the Protection of People with Mental Illness • National Mental Health Strategy • National Mental Health Policy • First National Mental Health Plan • Australian Medicare Agreements, including those relating to access to specific mental health services
1996	• National Standards for Mental Health Services (11 standards)
1998	• Second National Mental Health Plan • Australian Health Care Agreements, including commitment to implement the National Standards for Mental Health Services
2001	• National Health Performance Framework • NSW Health. Mental Health Outcomes and Assessment Statistics (MH-OAT) Data Collection: Reporting and Submission Requirements.
2002	• National Practice Standards for the Mental Health Workforce (12 standards) • National Outcomes and Casemix Collection • NSW Framework for Housing
2003	• Third National Mental Health Plan • Australian Health Care Agreements, including focus on safety and quality of mental health reform • National Strategic Framework for Aboriginal and Torres Strait Islander Health
2007	• NSW Community Mental Health Strategy 2007 - 2012
2008	• NSW Multicultural Mental Health Plan 2008 - 2012
2009	• Fourth National Mental Health Plan • NSW Health, NGO Drug and Alcohol and Mental Health Information Management Project • Physical Health Care of Mental Health Consumers Guidelines

Appendix G

Comprehensive Data Set

Note: This is not yet an ***Agreed Data Set***[86]

The DMS Comprehensive Data Set has been developed to capture the data collection and funding requirements of diverse CMOs working in 7 program types in NSW. It is noted that the CDS may not include all possible data elements for CMOs working in mental health in NSW. It is also considered that CMO's and government agencies will over time request additional data fields to meet their organisational needs, or hide data fields that are not required by the service.

	Comprehensive Data Set	
Key Domains1.	**Client Identification**	**METeOR ID No.**
1.1	Client Unique Identifier (automated)	290046
1.2.1	Client: Title	287166
1.2.2	Client: Family Name	286953
1.2.3	Client: Given Name	287035
1.2.4	Client: Alias Name	New
1.2.5	Client: Preferred Name	New
1.3	Client: Gender	New
1.4	Client: Sexuality	New
1.5	Client: Date of Birth	287007
1.6.1	Building/Unit Type	270023
1.6.2	Building/Unit Number	270018
1.6.3	House Number	270030
1.6.4	Street Name	270019
1.6.5	Street Type	270020
1.6.6	Suburb	287326
1.6.7	Residential Postcode	287224
1.7.1	Telephone Number	270266
1.7.2	Telephone Number Type	270299
1.7.3	Email Address	287469
1.7.4	Preferred Contact Method	Adaptation 287519

---

[86] While these data sets are aligned with the current data requirements of the major funders, a process of achieving agreement with Government funders will be undertaken in Phase 2 of the Data Management Strategy. As the largest funder in NSW, MHCC continues to work with NSW Health to reach agreement on the Minimum and Comprehensive Data Sets so that CMOs can be assured of meeting all data reporting requirements. MHCC hopes to release an addendum to this report with minor corrections and/or adjustments when an Agreed Data Set is established. Reaching agreement with other major funders of CMOs is on the agenda of the Data Management Strategy.

	Comprehensive Data Set	
1.8.1	Emergency Contact Name	New
1.8.2	Emergency Contact Telephone Number	New
1.9	Health Professionals Contact Information	New
1.10	Marital Status	291045
1.11.1	Aboriginal Status	Adaptation 291036
1.11.2	Torres Strait Islander Status	Adaptation 291036
1.12.1	Aboriginal Nation	New
1.12.2	Country / Nation of Mother / Grandmother	New
1.12.3	Country / Nation of Father / Grandfather	New
1.13	Country of Birth	370943
1.14	Cultural Identification	New
1.15	Main Language other than English spoken at Home	304133
1.16	Residency Status	New
1.17	Period of Residence in Australia	270050
2.A	**Client Characteristics**	**METeOR ID No.**
2.1	Consent Obtained Indicator	338737 NCSDD
2.2	Review Date of Consent	New
2.3	Interpreter Service Required	304294
2.4	Reason for Seeking Assistance (for new clients only)	337012 NCSDD
2.5	Referral Receipt Date	270005
2.6	Referral Source	297469 NCSDD
2.7	Accommodation Type	270088
2.8	Living Arrangement	270385 NCSDD
2.9.1	Children under 16 years living in Household	New
2.9.2	Child: Family Name	New
2.9.3	Child: Given Name	New
2.9.4	Child: Date of Birth	New
2.9.5	Child: Gender	New
2.10.1	Children under 16 years Not living in Household – Has Contact	New
2.10.2	Child: Family Name	New
2.10.3	Child: Given Name	New
2.10.4	Child: Date of Birth	New
2.10.5	Child: Gender	New

	Comprehensive Data Set	
2.11	Number of Children No Contact	New
2.12	Persons over 16 years Living in the Household that require Care	New
2.13.1	Other Persons: Family Name	New
2.13.2	Other Persons: Given Name	New
2.13.3	Other Persons: Date of Birth	New
2.13.4	Other Persons: Gender	New
2.14	Reason for Care	New
2.15	Source of Income	321156 NCSDD
2.16	Additional Income Source	Adaptation 321156 NCSDD
2.17	Level of Highest Educational Attainment	321069 NCSDD
2.18	Primary Carer Nominated	Adaptation 320939
2.19.1	Carer - Relationship to Care Recipient	270012
2.19.2	Carer: Family Name	286953
2.19.3	Carer: Given Name	287035
2.19.4	Carer: Alias Name	New
2.19.5	Carer: Preferred Name	New
2.20	Consent Provided to Contact Primary Carer	New
2.21.1	Building/Unit Type	270023
2.21.2	Building/Unit Number	270018
2.21.3	House Number	270030
2.21.4	Street Name	270019
2.21.5	Street Type	270020
2.21.6	Suburb	287326
2.21.7	Residential Postcode	287224
2.22.1	Telephone Number	270266
2.22.2	Telephone Number Type	270299
2.23	Email Address	287469
2.24	Preferred Contact Method for Primary Carer	Adaptation 287519
2.B	**To be completed by Carer services only – Carer-specific and Care Recipient (person receiving care)**	**METeOR ID No.**
2B.1	Number of People Caring for	New
2B.2	Length of Time in Caring Role	New
2B.3	Carer Life Cycle Stage	New
2B.4	Does the Care Recipient Live with You	New
2B.5	Consent Obtained Indicator – Care Recipient	Adaptation

	Comprehensive Data Set	
		338737 NCSDD
2B.6	Review Date of Consent	New
2B.7	Interpreter Service Required for Care Recipient	304294
2B.8.1	Care Recipient: Title	287166
2B.8.2	Care Recipient: Family Name	286953
2B.8.3	Care Recipient: Given Name	287035
2B.8.4	Care Recipient: Preferred Name	New
2B.9	Care Recipient: Gender	New
2B.10	Care Recipient: Date of Birth	287007
2B.11	Reason for Care	New
2B.12.1	Care Recipient: Building/Unit Type	270023
2B.12.2	Care Recipient: Building/Unit Number	270018
2B.12.3	Care Recipient: House Number	270030
2B.12.4	Care Recipient: Street Name	270019
2B.12.5	Care Recipient: Street Type	270020
2B.12.6	Care Recipient: Suburb	287326
2B.12.7	Care Recipient: Residential Postcode	287224
2B.13.1	Care Recipient: Telephone Number	270266
2B.13.2	Care Recipient: Telephone Number Type	270299
2B.14	Care Recipient: Email Address	287469
2B.15	Care Recipient: Preferred Method of Contact	Adaptation 287519
2B.16.1	Children under 16 years Living in the Care Recipient's Household	New
2B.16.2	Child: Family Name	New
2B.16.3	Child: Given Name	New
2B.16.4	Child: Date of Birth	New
2B.16.5	Child: Gender	New
2B.17.1	Children under 16 years Not Living in the Care Recipient's Household – Has Contact	New
2B.17.2	Child: Family Name	New
2B.17.3	Child: Given Name	New
2B.17.4	Child: Date of Birth	New
2B.17.5	Child: Gender	New
2B.18	Service Activity Type - Accessed by Care Recipient	270478 NCSDD
2.C	**To be completed for Client or Care Recipient**	**METeOR ID No.**
2.25	Clients Perceived Diagnosis	New
2.26	Principal Documented Diagnosis	Adaptation 391326
2.27	Additional Mental Health Diagnosis	New
2.28	Additional Other Diagnosis	Adaptation

	Comprehensive Data Set	
		391322
2.29	Additional Comorbidity Factor	New
2.30	Activity and Participation in Life Area	320125
2.31	Level of Difficulty with Activities in Life Areas	320120
2.32	Employment / Vocational Status	Adaptation 314867 NCSDD
2.33	Occupation	Adaptation 350899
2.34	Employment History	New
2.35	Individual Plan Indicator	Adaptation 321129 NCSDD
2.36	Individual Goals	New
2.37	Medication	New
2.38	Protective Factors	New
2.39	Risk Factors	Link to 270338
2.40	Risk Assessment Completion Date	New
2.41	Risk/s Identified from Risk Assessment	New
2.42	Risk Intervention	Adaptation 270165
2.43	Current Legal Status (NSW)	New
2.44	Legal Order	324835 NCSDD
2.45	Management Plan Review Date	New
2.46	Forensic History	New
2.47	Total Length of Stay in Psychiatric Hospital	Adaptation 270300
3.	**Participation / Program Use**	**METeOR ID No.**
3.1	Individual Assessment Date	New
3.2	Service Start Date	338558 NCSDD
3.3	Service End Date	270160 NCSDD
3.4	Service Cessation Reason	270099 NCSDD
3.5	Service Contact	New
3.6	Method of Service	Adaptation 286832 & 319817 NCSDD

	Comprehensive Data Set	
3.7	Service Activity Type	Adaptation 270478 NCSDD
3.8.1	Hours of Service per Contact - Direct	New
3.8.2	Hours of Service per Contact - Indirect	New
3.9.1	Hours of Transport per Contact - Direct	New
3.9.2	Hours of Transport per Contact - Indirect	New
3.10	Individual Plan Commencement Date	New
3.11	Individual Plan Review Date	New
3.12	Service / Other Agency Use on Entry	New
3.13	Satisfaction Survey Completion Date	New
3.14	Referrals to Other Agencies	New
3.15	Link with Culturally Specific Activities / Agencies	New
3.16	Service / Other Agency Use on Exit	New
3.17	Ongoing Engagement > Active / Inactive	New
4.	**Outcome Measures – Examples**	
4.1	K10+ (Kessler 10)	
4.2	CANSAS (Camberwell Assessment of Need Short Appraisal Schedule)	
4.3	Quality of Life Scale (WHO-QOL)	
4.4	Personal Wellbeing Index - Australia (PWI-A)	
4.5	Satisfaction with Life Scale (SWLS)	
4.6	Life Skills Profile (LSP 16 or 39)	
4.7	DASS (Depression Anxiety Stress Scales)	
4.8	Severity of Dependence Scale (SDS)	
4.9	CEO-NGO (Consumer Evaluation of NGOs)	
4.10	STORI (Stage of Recovery Instrument)	
4.11	GEM (Growth and Empowerment Measure)	
4.12	ASSIST (Alcohol, Smoking and Substance Involvement Screening Tool)	
4.13	BASIS-32 (Behaviour and Symptom Identification Scale)	
4.14	CAARMS (Comprehensive Assessment of At Risk Mental States)	
4.15	APQ6 (Activity and Participation Questionnaire)	
4.16	HoNOS (Health of the Nation Outcome Scale)	
4.17	GAF (Global Assessment of Functioning)	
4.18	RUG-ADL (Resource Utilisation Group - Activities of Daily Living)	
5.	**Organisation & Program Identification / Characteristics**	**METeOR ID No.**
5.1	Organisation Name	288917

	Comprehensive Data Set	
5.2	Program Name Type	288937
5.3	Funding Source/s	New
5.4	Number of Funded Client Packages	New
5.5	Number of Unfunded Client Packages	New
5.6	Brokerage Agreement Number	New
5.7	Program Suburb	290059
5.8	Program Postcode	290064
5.9	Region of Service	Combination - 295808; 307282 NCSDD; 386789 NCSDD
5.10	Service Type	New
5.11	Program Delivery Setting	319826 NCSDD
5.12	Community Education Services Provided	New
5.13	Funded to undertake Community Education	New
5.14	Formal Continuous Quality Improvement	New
5.15	Recognised Accreditation	New
5.16	Accreditation Source	New
6.	**Workforce Summary Data** **(Data is drawn from a HR or payroll database)**	**METeOR ID No.**
6.1	Workforce FTE	New
6.2	Volunteers FTE	Adaptation 270214 NCSDD
6.3	Length of Staff Employment in Current Service	315084 NCSDD
6.4	Number of Staff Employed as Consumer Workers	New
6.5	Number of Staff Employed as Carer Workers	New
6.6	Number of Staff who identify as Consumers	New
6.7	Number of Staff with lived Experience as Carers	New
6.8	Number of Staff with Mental Health First Aid Certificates	New
6.9	Number of Staff with Aboriginal Mental Health First Aid Certificates	New
6.10.1	Qualifications of Staff Certificate III Level	New
6.10.2	Qualifications of Staff Certificate IV	New
6.10.3	Qualifications of Staff Diploma / Associate Diploma Level	New
6.10.4	Qualifications of Staff Degree Level	New
6.10.5	Qualifications of Staff Post Graduate Degree /	New

	Comprehensive Data Set	
	Diploma Level	
6.11	Number of First Aid Certificates	New
6.12	Age Range - Workforce	Adaptation 290540
6.13	Gender - Workforce	New
6.14	Number of Staff who identify as Aboriginal	New
6.15	Number of Staff who identify as Torres Strait Islander	New
6.16	Number of Staff who identify from Cultural and Linguistically Diverse Backgrounds	New
6.17	Languages other than English spoken - Workforce	Adaptation 304133
6.18	Number of Staff who Identify as having a Disability	New
6.19	Workforce Wellbeing Monitor 6 monthly	New
6.20	Workplace Satisfaction Survey	New
6.21	Professional Development Plans	New

Legend:

- National Health Data Dictionary = METeOR ID number is for data elements from the National Health Data Dictionary unless stated otherwise.
- NCSDD = National Community Services Data Dictionary
- New = New data element
- Adaptation = Adaption of the existing data dictionary data element
- Combination = Components of two data elements have been combined to form one relevant data element.

Appendix H

Inclusion and Exclusion Rationales for New and Adapted Data Elements for the Comprehensive Data Set for Community-Managed Organisations (CMOs) Working in Mental Health in NSW as at 5 June 2010

Key Domain No.	Data Element	Inclusion, Adaptation or Exclusion Rationale
Domain 1	**Client Identification**	
1.1	Client Unique Identifier (automated)	• Will be automated to allow a new client to be registered in the system. • Required for relational databases. Relational databases enable you to search client records such that the unique identifier links the records. • Unique identifiers are organization-specific and do not facilitate transfer of information to third parties. • The amenity does permit researchers to access this information but requires client consent so as not to breach privacy legislation.
1.2.1	Client: Title	• The definition of title remains the same with the prefix of Client as a descriptor providing clarity to the database
1.2.2	Client: Family Name	• The definition of family name remains the same with the prefix of Client as a descriptor providing clarity to the database
1.2.3	Client: Given Name	• The definition of person name remains the same with the prefix of Client as a descriptor providing clarity to the database
1.2.4	Client: Alias Name	• It is acknowledged that some people use more than one given name, e.g. formal name, birth name, nickname, shortened name, or tribal name, depending on the circumstances.
1.2.5	Client: Preferred Name	• Sensitivity to client individual choice and is the name client prefers to be socially identified by.

Key Domain No.	Data Element	Inclusion, Adaptation or Exclusion Rationale
1.3	Client: Gender	Add Transgender; Add Not Specified • Will record Male; Female; Intersex/Indeterminate; Transgender; Not stated; Not specified • Due to sensitivity to client preferences Gender is the preferred term to Sex as recorded in METeOR ID 287316 Person-Sex • Social identification of a person and self-reported • FAHCSIA (PHAMS program) utilize this terminology to define client-identified gender
1.4	Sexuality	• Respectful and validating of an individual • May be an additional area that an individual may benefit from support or referral • There is no standard state or national data collection around sexual identity. Collection of data will benefit the development of policies and programs and improve standards of care • Data element asks: Do you identify as? • Record: Heterosexual; Gay Man; Lesbian; Bisexual; Other
1.5	Client: Date of Birth	• Age changes whereas date of birth is input once. Date of birth also assists with identification of clients with common surnames e.g. Ng; Smith • Age can be automated once date of birth is entered • If date of birth is not known or cannot be obtained provision should be made to estimate age. • Age is calculated automatically. • Estimated date of birth is acceptable and should be flagged (a date accuracy indicator). • METeOR ID 303794 Person - Age, total years is not adequate

Key Domain No.	Data Element	Inclusion, Adaptation or Exclusion Rationale
	Medicare Card Number	Excluded - METeOR ID 270101 Medicare Card Number • CMOs absorb the cost in the majority of occasions • Medicare numbers are not required as a routine collection item.
1.7.4	Preferred Method of Contact	Adaptation of METeOR ID 287519 Electronic Communication Medium • The mode of communication a person prefers to be contacted by. • Expansion of the code to include non-electronic modes of communication. • Additional items are: face-to-face, letter, home telephone / work telephone, via third party telephone, SMS, Skype.
1.8.1	Emergency Contact Name	• Contact for CMO to call in case of emergency
1.8.2	Emergency Contact Telephone	• Contact for CMO to call in case of emergency
1.9	Health Professionals Contact Information	• Includes General Practitioner, Community Mental Health Case Manager, Psychiatrist, Psychologist, Medical Specialists and Podiatrists etc. • Provides comprehensive information on types of health care services received • Assists with linkages and the coordination of client support.
1.11.1	Aboriginal Status	Adaptation of METeOR ID 291036 Indigenous Status • Use of the two terms Aboriginal Status and Torres Strait Islander Status separately and instead of Indigenous. • Respectful and validating of the first people of Australia • Definition to include title 'Australian Aboriginal...' • Records: Yes / No / Not known
1.11.2	Torres Strait Islander Status	Adaptation METeOR ID 291036 Indigenous Status • Use of the two terms Aboriginal Status and Torres Strait Islander Status separately

Key Domain No.	Data Element	Inclusion, Adaptation or Exclusion Rationale
		and instead of Indigenous. • Respectful and validating of the first people of Australia • Records: Yes / No / Not known
1.12.1	Aboriginal Nation	• Understanding where an Aboriginal or Torres Strait Islander person is from is culturally appropriate and respectful. • Recommend link to Aboriginal Australia Map, Australian Institute of Aboriginal and Torres Strait Islander Studies • The Australian Bureau of Statistics provides a standard for the publication of Census data about the Indigenous population. It was deemed inappropriate for this Data Dictionary due to its focus on government regions.
1.12.2	Country / Nation of Mother / Grandmother	• Aborigines define themselves as belonging to the country / nation of their mother / grandmother.
1.12.3	Country / Nation of Father / Grandfather	• Aborigines define themselves as belonging to the country / nation of their father / grandfather.
1.14	Cultural Identification	• Individuals identify with a particular cultural background. • This is not often recognized and may benefit in the provision of services that are culturally sensitive and inclusive of families and carers. • In line with the Australian Standard Classification of Cultural and Ethnic Groups, ABS Document no. 1249.0, 2nd Edition
1.16	Residency Status	• Data collection provides insight into the type of services that may be required for the client e.g. for a refugee • Provides CMOs with information as to what services can be provided e.g. access to Medicare.

Key Domain No.	Data Element	Inclusion, Adaptation or Exclusion Rationale
		• Includes Permanent resident; Temporary resident; Temporary Protection Visa; Asylum seeker, Refugee, Student / Working Visa etc
Domain 2A	**Client Characteristics**	
2.2	Review Date of Consent	• Under state and federal privacy legislation consent is required for release of information • Recommend that a review of the written consent occur annually.
2.9.1	Children under 16 years living in Household	• In line with the NSW Government's 'Keep them Safe: A shared approach to child wellbeing' • Records: Yes / No
2.9.2	Child: Family Name	• In line with the NSW Government's 'Keep them Safe: A shared approach to child wellbeing' • The definition of family name remains the same with the prefix of Child as a descriptor providing clarity to the database
2.9.3	Child: Given Name	• In line with the NSW Government's 'Keep them Safe: A shared approach to child wellbeing' • The definition of person name remains the same with the prefix of Child as a descriptor providing clarity to the database
2.9.4	Child: Date of Birth	• In line with the NSW Government's 'Keep them Safe: A shared approach to child wellbeing' • The definition of date of birth remains the same with prefix of Child as a descriptor providing clarity to the database • Age changes whereas date of birth is input once. Date of birth also assists with identification of children with common surnames e.g. Ng; Smith • Age can be automated once date of birth is entered.

Key Domain No.	Data Element	Inclusion, Adaptation or Exclusion Rationale
2.9.5	Child: Gender	• The definition of gender remains the same with the prefix of Child as a descriptor providing clarity to the database
2.10.1	Children under 16 years Not living in Household – Has Contact	• In line with the NSW Government's 'Keep them Safe: A shared approach to child wellbeing' • Records: Yes / No
2.10.2	Child: Family Name	• In line with the NSW Government's 'Keep them Safe: A shared approach to child wellbeing' • The definition of family name remains the same with the prefix of Child as a descriptor providing clarity to the database
2.10.3	Child: Given Name	• In line with the NSW Government's 'Keep them Safe: A shared approach to child wellbeing' • The definition of person name remains the same with the prefix of Child as a descriptor providing clarity to the database
2.10.4	Child: Date of Birth	• In line with the NSW Government's 'Keep them Safe: A shared approach to child wellbeing' • The definition of date of birth remains the same with prefix of Child as a descriptor providing clarity to the database • Age changes whereas date of birth is input once. Date of birth also assists with identification of children with common surnames e.g. Ng; Smith • Age can be automated once date of birth is entered.
2.10.5	Child: Gender	• The definition of gender remains the same with the prefix of Child as a descriptor providing clarity to the database
2.11	Number of Children No Contact	• No data currently collected • Will assist to identify people's loss of contact with their children

Key Domain No.	Data Element	Inclusion, Adaptation or Exclusion Rationale
		• This could be an additional area that requires support for the individual.
2.12	Persons over 16 years living in the Household that Require Care	• This information identifies people living in the household who are reliant on the client for support. • Particularly relevant if client is hospitalized • Records: Yes / No
2.13.1	Other Persons: Family Name	• The definition of family name remains the same with the prefix of Other Persons as a descriptor providing clarity to the database
2.13.2	Other Persons: Given Name	• The definition of person name remains the same with the prefix of Other Persons as a descriptor providing clarity to the database
2.13.3	Other Persons: Date of Birth	• The definition of date of birth remains the same with the prefix of Other Persons as a descriptor providing clarity to the database • Age can be automated once date of birth is entered.
2.14	Reason for Care	• Defines the support being provided. • Includes: aged, disability, substance dependence, physical disability, psychiatric disability, intellectual disability, other
2.16	Additional Income Source	Adaptation of METeOR ID 321156 Source of Income NCSDD • Allows for the recording of additional income sources
2.18	Primary Carer Nominated	Adaptation of METeOR ID 320939 Informal carer existence indicator • The client identifying their carer provides a holistic approach to the services provided and identifies other avenues of support within the client's life.
2.19.2	Carer: Family Name	• The definition of family name remains the same with the prefix of Carer as a descriptor providing clarity to the database
2.19.3	Carer: Given Name	• The definition of person name remains the same with the prefix of Carer as a

Key Domain No.	Data Element	Inclusion, Adaptation or Exclusion Rationale
		descriptor providing clarity to the database
2.19.4	Carer: Alias Name	• The definition of alias name remains the same with the prefix of Carer as a descriptor providing clarity to the database
2.19.5	Carer: Preferred Name	• The definition of preferred name remains the same with the prefix of Carer as a descriptor providing clarity to the database
2.19.6	Carer: Gender	• The definition of gender remains the same with the prefix of Carer as a descriptor providing clarity to the database
2.20	Consent Provided to Contact Primary Carer	• Client nominates the carer, therefore client consent is required to ensure privacy and confidentiality is maintained. • Records: Yes / No / Not known
2.24	Preferred Contact Method for Primary Carer	Adaptation of METeOR 287519 Electronic Communication Medium • The mode of communication a person prefers to be contacted by. • Expansion of the codes to include non-electronic modes of communication. • Additional items are: face-to-face, letter, home telephone / work telephone, via third party telephone, SMS and Skype.
Domain 2B	**Carer-Specific and Care Recipient Services**	
2B.1	Number of People Caring for	• To assist with the identification and assessment of carer needs
2B.2	Length of Time in Caring Role	• Assists with exposing hidden carers and identifying the needs of carers
2B.3	Carer Life Cycle Stage or Carer Life Course Framework	• Both frameworks assist to target support, determine required resources and develop relevant services • May record: First Time, Early, Experienced, Veteran or Carer Life Course

Key Domain No.	Data Element	Inclusion, Adaptation or Exclusion Rationale
		Framework
2B.4	Does the Care Recipient live with you	• Record: Yes / No / Not stated • No additional information required
2B.5	Consent Obtained Indicator - Care Recipient	Adaptation of METeOR ID 338738 Client – Consent Obtained Indicator, NCSDD • Written consent to obtain and release information about the care recipient. • Provides ability to contact the care recipient, where appropriate • Record: Yes / No / Not yet determined
2B.6	Review Date of Consent	• Under state and federal privacy legislation consent is required for the release of information • Recommend that the review of the written consent occur annually.
2B.8.4	Care Recipient: Preferred Name	• The definition of preferred name remains the same with the prefix of Care Recipient as a descriptor providing clarity to the database
2B.9	Care Recipient: Gender	Add Transgender; Add Not Specified • Will record Male; Female; Intersex / Indeterminate; Transgender; Not stated; Not specified • Due to sensitivity to client preferences Gender is the preferred term to Sex as recorded in METeOR ID 287316 Person-Sex
2B.10	Care Recipient: Date of Birth	• The definition of date of birth remains the same with the prefix of Care Recipient as a descriptor providing clarity to the database • Age changes whereas date of birth is input once. Date of birth also assists with identification of individuals with common surnames e.g. Ng; Smith • Age can be automated once date of birth is entered.
2B.11	Reason for Care	• Defines the support provided. • For example: Aged, disability, substance dependence, physical disability, psychiatric

Key Domain No.	Data Element	Inclusion, Adaptation or Exclusion Rationale
		disability, intellectual disability, other
2B.15	Care Recipient: Preferred Method of Contact	Adaptation of METeOR ID 287519 Electronic Communication Medium • The mode of communication a person prefers to be contacted by. • Expansion of the code to include non-electronic modes of communication. • Additional items are: face-to-face, letter, home telephone / work telephone, via third party telephone, SMS and Skype.
2B.16.1	Children under 16 years Living in the Care Recipient's Household	• In line with the NSW Government's 'Keep them Safe: A shared approach to child wellbeing' • Provides for a Yes / No response
2B.16.2	Child: Family Name	• In line with the NSW Government's 'Keep them Safe: A shared approach to child wellbeing' • The definition of person name remains the same with the prefix of Child as a descriptor providing clarity to the database • Ability to record information on multiple children, where necessary
2B.16.3	Child: Given Name	• In line with the NSW Government's 'Keep them Safe: A shared approach to child wellbeing' • The definition of person name remains the same with the prefix of Child as a descriptor providing clarity to the database
2B.16.4	Child: Date of Birth	• In line with the NSW Government's 'Keep them Safe: A shared approach to child wellbeing' • The definition of date of birth remains the same with the prefix of Child as a descriptor providing clarity to the database • Age can be automated once date of birth is entered.
2B.16.5	Child: Gender	• In line with the NSW Government's 'Keep them Safe: A shared approach to child

Key Domain No.	Data Element	Inclusion, Adaptation or Exclusion Rationale
		wellbeing' - The definition of gender remains the same with the prefix of Child as a descriptor providing clarity to the database
2B.17.1	Children under 16 years Not Living in the Care Recipient's Household – Has Contact	- In line with the NSW Government's 'Keep them Safe: A shared approach to child wellbeing' - Provides for a Yes / No response
2B.17.2	Child: Family Name	- In line with the NSW Government's 'Keep them Safe: A shared approach to child wellbeing' - The definition of person name remains the same with the prefix of Child as a descriptor providing clarity to the database - Ability to record information on multiple children, where necessary
2B.17.3	Child: Given Name	- In line with the NSW Government's 'Keep them Safe: A shared approach to child wellbeing' - The definition of person name remains the same with the prefix of Child as a descriptor providing clarity to the database
2B.17.4	Date of Birth of Children	- In line with the NSW Government's 'Keep them Safe: A shared approach to child wellbeing' - The definition of date of birth remains the same with the prefix of Child as a descriptor providing clarity to the database - Age can be automated once date of birth is entered.
2B.17.5	Child: Gender	- In line with the NSW Government's 'Keep them Safe: A shared approach to child wellbeing' - The definition of gender remains the same with the prefix of Child as a descriptor providing clarity to the database

Key Domain No.	Data Element	Inclusion, Adaptation or Exclusion Rationale
2B.18	Service Activity Type - Access by Care Recipient	• Identification of services currently being received • Assists with identifying gaps and improving care coordination • For example: centre based; in home; host family; flexible respite; overnight care; recreation; peer support – care recipient and carer; education/ training; other
Domain 2C	**Client or Care Recipient**	
2.25	Clients Perceived Diagnosis	• This data element supports self-managed recovery processes • Item will record Nil Diagnosis
2.26	Principal Documented Diagnosis	Adaptation of METeOR ID 391326 Episode of care – Principle Diagnosis • Addition of word – Documented. • Diagnosis may vary over time, with different health assessments and health professionals. • This addition also supports the validity of the client's perceived diagnosis.
2.27	Additional Mental Health Diagnosis	• It is common for people to have more than one mental health problem.
2.28	Additional Other Diagnosis	Adaptation of METeOR ID 391322 Episode of care – Additional diagnosis, code • It is common for people to have a number of health-related problems • Diagnosis may vary over time with different health assessments
2.29	Additional Comorbidity Factor	• This is relevant where two or more co-existing conditions are impacting on an individual's ability to function to potential. These conditions may not involve a diagnosis. • For example: Alcohol and Drug Use; Acquired Brain Injury; Intellectual Disability; Physical Health Impairment; Ageing issues
2.32	Employment / Vocational	Adaptation of METeOR ID 314867 Employment Type NCSDD

Key Domain No.	Data Element	Inclusion, Adaptation or Exclusion Rationale
	Status	• To include volunteer status • Working as a volunteer may assist with recovery processes
2.33	Occupation	Adaptation of METeOR ID 350899 Main Occupation • Identifies strengths to assist with employment or skill-sharing • Data would collect information on current and past occupation • Provides demographic data
2.34	Employment History	• Identification of employment history assists with recovery-oriented approaches • Data not currently collected
2.35	Individual Plan Indicator	Adaptation of METeOR ID 321129 Case management plan indicator NCSDD: 'Whether or not a current (at the time of recording) case management plan has been developed for the client, as represented by a code'. • A record of the individual plan will enable all staff involved in the provision of support to a consumer to have ready access to the plan to ensure a consistent approach to care and support. • Records: Yes / No / Not Stated • The recording of the date of creation will ensure regular revisions of the individual plan. • Records: Date of creation 00/00/0000
2.36	Individual Goals	• A recovery approach to service provision requires an understanding and the recording of individual goals, thereby enabling a consistent approach to service delivery and ensures goals are created in partnership with the client.
2.37	Medication	• An accurate record of medication will support holistic care and assist with any emergency situations.
2.38	Protective Factors	• Recognition of factors aids an individual's identity and recovery process.

Key Domain No.	Data Element	Inclusion, Adaptation or Exclusion Rationale
		- Includes: Connection with family, community and social networks; Responsibility of caring for children; Significant other person; resilience and problem-solving abilities; Physical and mental health; Spirituality; Early identification and/or appropriate treatment of mental illness; Other - Collection of this data is not available through outcome measures.
2.39	Risk Factors	Link to METeOR ID 270338 Behaviour – related risk factor intervention purpose - This is an expansion of risk factors to assist individuals to identify own risks. - The NHDD data element has a focus on behaviour related risk factors and does not capture social economic, historic and the broader range of risk factors that may impact on service engagement. - Includes: Family history of mental illness; Alcohol and other drugs; Family difficulties; Custody issues; Domestic violence; Abuse; History of Suicide Attempt/s; Family history of suicide/suicidal behaviour; History of Self-Harming Behaviour; Grief and loss; Socio-economic disadvantage; Legal or Financial problems; Problem Gambling; History of recent Violence towards Others; Conflict over sexual identity or other sexual issues; Work related stress; Other - Data collection will assist CMOs to provide holistic support.
2.40	Risk Assessment Completion Date	- Ensures risk assessments are completed in a timely manner
2.41	Risk/s identified from Risk Assessment	- Assists with identification and management of risk/s
2.42	Risk Intervention	Adaptation from METeOR ID 270165 Episode of care – Behaviour-related risk factor intervention - Needs to be CMO specific and not related to episode of care

Key Domain No.	Data Element	Inclusion, Adaptation or Exclusion Rationale
2.43	Current Legal Status	• This is specific to NSW and identifies legal issues and supports for a client • Includes: Trustee in Guardian; Community Treatment Order; Apprehended Violence Order; Forensic Order; Probation & Parole; Power of Attorney; Enduring Guardian; Court Order
2.45	Management Plan Review Date	• Optimises service provision and ensures currency
2.46	Forensic History	• Voluntary disclosure • There are now specific mental health funded transition and post-release from prison CMO programs
2.47	Total Length of Stay in Psychiatric Hospital	• Adaptation - Existing METeOR ID 270300 Episode of Care – number of psychiatric care days total, is for clinical mental health services, and does not relate to CMOs. • However data is being collected each quarter by CMOs, for example the NSW Health Housing and Accommodation Support Initiative (HASI) programs. • It is believed this is a duplication of data as being collected by clinical services. • However it may provide CMO and funding bodies with evidence-based outcomes
Domain 3	**Participation / Program Use**	
3.1	Individual Assessment Date	• Date of assessment with client to determine eligibility • Assists with determining waiting time between individual assessment date and program entry date
3.5	Service Contact	• Provides a CMO with the opportunity to determine whether the contact is one-off or ongoing contact. • This is collected each contact and is linked to CDS data items 3.7 – 3.9

Key Domain No.	Data Element	Inclusion, Adaptation or Exclusion Rationale
3.6	Method of Service Delivery	Adaptation of METeOR IDs 286832 - Mental Health Service Contact session type and ID 319817 - Service Delivery Setting Code NCSDD, as combine's characteristics of both data elements. • Include 1:1, group, letter, fax, telephone, email, via third party, SMS, Skype etc
3.7	Service Activity Type	Adaptation of METeOR ID 270478 Service Provider Organization – service Activity Type, NCSDD • Needs to be inclusive of full range of CMO activities, i.e. Helpline and Counselling Services; Self-Help and Peer Support; Accommodation Support and Outreach programs; Employment and Education; Family Support and Carer Programs; Information, Advocacy and Promotion; Leisure and Recreation • Activity types as per funding agreements
3.8.1	Hours of Service per Contact - Direct	• Actual hours of service per contact entered by staff • Hours of direct client services delivered • Collation of contact hours will match against funding agreement
3.8.2	Hours of Service per Contact - Indirect	• Hours of indirect client services provided • Information collected may assist with identifying variance • Collation of contact hours will match against funding agreement
3.9.1	Hours of Transport per Contact - Direct	• Hours of direct client transport • As per funding agreements
3.9.2	Hours of Transport per Contact - Indirect	• Hours of transport in relation to client, when a client is not present
3.10	Individual Plan Commencement Date	• All CMOs have consumers actively involved in their individual plans • Includes all plans i.e. Recovery; Support; Service; Care • Quality improvement measure

Key Domain No.	Data Element	Inclusion, Adaptation or Exclusion Rationale
3.11	Individual Plan Review Date	• Ensures consistent client support • Quality improvement measure
3.12	Service / Other Agency Use on Entry	• Determines other support services being accessed by the client at time of program entry • Also useful for identifying gaps and improved care coordination • State and locality specific • Includes: Peer Support Group or Activity; GP; Psychiatrist; NA/AA; Community Mental Health service; Clubhouse; Alcohol & Other Drugs; Inpatient Unit; Depot Clinic; Psychologist; Carer Support Group; Commonwealth Carelink; HACC service; Aged Care; COPMI; Youth service; Aboriginal or Torres Strait Islander service/group; Culturally-specific support group; Counselling service; CMO group; Other government agency; Complementary therapy centre; Other
3.13	Satisfaction Survey Completion Date	• Annual completion • Encourages consumer/carer feedback on service quality • In line with evidence-based practice and the Fourth National Mental Health Plan Priority 4: Quality Improvement and Innovation Indicator for monitoring change • MH-COPES is not for CMOs
3.14	Referrals to Other Agencies	• Identifies specific referrals to other agencies on behalf of the client • May be a requirement of funding performance indicators • State and locality specific • Includes: Peer Support Group or Activity; GP; Psychiatrist; NA/AA; Community Mental Health service; Clubhouse; Alcohol & Other Drugs; Inpatient Unit; Depot Clinic; Psychologist; Carer Support Group; Commonwealth Carelink; HACC service; Aged Care; COPMI; Youth service; Aboriginal or Torres Strait Islander service/group; Culturally-specific support group; Counselling service; CMO group;

Key Domain No.	Data Element	Inclusion, Adaptation or Exclusion Rationale
		Other government agency; Complementary therapy centre; Other
3.15	Link with Culturally Specific Activities / Agencies	• Enhancing linkages respects consumers' personal, cultural and spiritual belief system, and that of their families, carers and community • In line with NSW Multicultural Mental Health Plan 2008 - 2012 • Record: Yes / No / Not Known / Not Required
3.16	Service / Other Agency Use on Exit	• Determine other support services being accessed by the client at time of program exit • Also useful for identifying gaps and improved care coordination • State and locality-specific • For example: Peer Support Group or Activity; GP; Psychiatrist; NA/AA; Community Mental Health service; Clubhouse; Alcohol & Other Drugs; Inpatient Unit; Depot Clinic; Psychologist; Carer Support Group; Commonwealth Carelink; HACC service; Aged Care; COPMI; Youth service; Aboriginal or Torres Strait Islander service/group; Culturally-specific support group; Counselling service; CMO group; Other government agency; Complementary therapy centre; Other
3.17	Ongoing Engagement	• Identifies whether the client is actively engaged or inactive but not exited from the program • For example: Funding requirement of FAHCSIA Personal Helpers and Mentors Program
Domain 4	**Outcome Measures**	
4	Outcome Measures	• A snapshot of sector-wide outcome measures that are evidence-based are provided • Examples of tools commonly used for assessment of client needs, monitoring and recovery processes, and funding requirements • Recommend use of K10+ and CANSAS

Key Domain No.	Data Element	Inclusion, Adaptation or Exclusion Rationale
		• Outcome measures can be added or hidden depending on CMO practice • It is expected that each CMO will have the required license for use, unless the measures are in the public domain
Domain 5	**Organisation & Program**	
5.3	Funding Source/s	• Collection of data will assist with the identification of the diverse funding sources to CMOs in NSW and Australia
5.4	Number of Funded Client Packages	• Number of client funding packages as per funding agreement per quarter
5.5	Number of Unfunded Client Packages	• Number of clients' provided services above funded packages per quarter
5.6	Brokerage Agreement Number	• As per funding requirement
5.9	Region of Service	Combination of METeOR IDs 295808 - Health Region; NCSDD ID 307282 - Region Identifier; and NCSDD ID 396789 - Geographic Location • Required to meet diversity of CMOs reporting requirements • Includes: Area Health Service regions; SAAP regions and Local Government Areas
5.10	Service Type	• Identifies the type of service being provided i.e. Helpline and Counselling Services; Self-Help and Peer Support; Accommodation Support and Outreach; Employment and Education; Family Support and Carer Programs; Information, Advocacy and Promotion; Leisure and Recreation • Recognizes the diversity of services provided by CMOs
5.12	Community Education Services Provided	• It is recognised that CMOs undertake numerous community education activities that are not otherwise captured • For example: Mental Health Week; Carers week; Rotary Forums; School forums

Key Domain No.	Data Element	Inclusion, Adaptation or Exclusion Rationale
		and programs; Information Kiosks; at Neighbourhood Centres
5.13	Funded to undertake Community Education	• Data is not currently collected • If funded, it provides evidence of meeting funding requirements • If not funded then demonstrates unfunded contribution of CMO sector • Also useful for identifying funding gaps
5.14	Formal Continuous Quality Improvement	• In line with evidence-based practice and the Fourth National Mental Health Plan Priority 4 Quality Improvement and innovation and National Mental Health Standards
5.15	Recognised Accreditation	• Mapping Sector data revealed low levels of accreditation by CMOs • In line with evidence-based practice and the Fourth National Mental Health Plan Priority 4 Quality Improvement and Innovation and National Mental Health Standards
5.16	Accreditation Source	• For example: QMS; QICSA; ACHS: ISO
Domain 6	**Workforce Summary Data**	
6.1	Workforce FTE	• CMOs full time equivalent paid staff comprising full time, part time and casual staff members • Data is not currently collected • Collection of this data would be in line with evidence-based practice
6.2	Volunteers FTE	Adaptation of METeOR ID 270214 Full-time equivalent staff (volunteer/unpaid) total, NCSDD • Data is not currently collected

Key Domain No.	Data Element	Inclusion, Adaptation or Exclusion Rationale
6.4	Number of Staff Employed as Consumer Workers	• Data demonstrates participation in the workforce of people with lived experience • In line with evidence-based practice and the Fourth National Mental Health Plan Priority 4, Indicator 1
6.5	Number of Staff Employed as Carer Workers	• Data demonstrates participation in the workforce of people with lived experience • In line with evidence-based practice and the Fourth National Mental Health Plan Priority 4, Indicator 1
6.6	Number of Staff who identify as consumers	• Voluntary disclosure of staff who identify as a consumer • Identifies level of participation in the mental health CMO workforce of people with lived experience
6.7	Number of Staff with lived Experience as Carers	• Voluntary disclosure of staff who identify as a carer • Identifies level of participation in the mental health CMO workforce of people with lived experience
6.8	Number of Staff with Mental Health First Aid Certificates	• Data collection provides evidence of professional non-clinical workforce • Data not currently collected • In line with National Mental Health Workforce Professional development Strategy
6.9	Number of Staff with Aboriginal Mental Health First Aid Certificates	• Data collection provides evidence of professional non-clinical workforce • Data not currently collected • In line with National Mental Health Workforce Professional Development Strategy
6.10.1	Qualifications of Staff Certificate III Level	• Data collection provides evidence of professional non-clinical workforce • Data not currently collected • In line with National Mental Health Workforce Professional Development Strategy
6.10.2	Qualifications of Staff Certificate IV Level	• Data collection provides evidence of professional non-clinical workforce • Includes Mental Health; Disability; Aged Care; AOD; Other

Key Domain No.	Data Element	Inclusion, Adaptation or Exclusion Rationale
		• Data not currently collected • In line with National Mental Health Workforce Professional Development Strategy
6.10.3	Qualifications of Staff Diploma / Associate Diploma Level	• Data collection provides evidence of professional non-clinical workforce • Data not currently collected • In line with National Mental Health Workforce Professional Development Strategy
6.10.4	Qualification of Staff Degree Level	• Data collection provides evidence of professional non-clinical workforce • Includes Nursing; Psychology; Social Work; Occupational Therapy • Data not currently collected • In line with National Mental Health Workforce Professional Development Strategy
6.10.5	Qualification of Staff Post Graduate Degree / Diploma Level	• Data collection provides evidence of professional non-clinical workforce • Data not currently collected • In line with National Mental Health Workforce Professional Development Strategy
6.11	Number of First Aid Certificates	• Data not currently collected • NSW OH&S legislation dictates needs for workforce to have first aid certificates
6.12	Age Range - Workforce	Adaptation of METeOR ID 290540 Person – age range, code. • To specify Workforce • Assists with identification and planning to address ageing workforce • Age ranges would be consistent with the standard 10 year ranges recommended by the ABS.
6.13	Gender - Workforce	• Gender: Male; Female; Intersex/Indeterminate; Transgender; Not stated; Not specified • Added Transgender and Not Specified • Gender is the preferred term to 'Sex' due to sensitivity to staff members preference

Key Domain No.	Data Element	Inclusion, Adaptation or Exclusion Rationale
		• Social identification of a person and self-reported
6.14	Number of Staff who identify as Aboriginal	• Data not currently collected • In line with the NSW Aboriginal Mental Health and Well Being Policy 2006 - 2010
6.15	Number of Staff who identify as Torres Strait Islander	• Data not currently collected • In line with the NSW Aboriginal Mental Health and Well Being Policy 2006 - 2010
6.16	Number of Staff who identify from Cultural and Linguistically Diverse Backgrounds	• Data not currently collected • In line with the National Mental Health Plan 2006 – 2011 and the NSW Multicultural Mental Health Plan 2008 - 2012
6.17	Languages other than English spoken - Workforce	Adaption of METeOR ID 304133 Main Language other than English spoken at Home • Application for workforce • Determines linguistic diversity of workforce • CMOs have a culturally diverse workforce but data is not collected
6.18	Number of Staff who Identify as having a Disability	• Demonstrates workplace diversity • Data not currently collected
6.19	Workforce Wellbeing Monitor	• Data not currently collected • Recommend 6-monthly distribution and collection to workforce • For example: use of K10+ • Enables comparison with national normative data
6.20	Workplace Satisfaction Survey	• De-identified annual staff satisfaction survey • Monitors workforce wellbeing and satisfaction • Data not currently collected

Key Domain No.	Data Element	Inclusion, Adaptation or Exclusion Rationale
6.21	Professional Development Plans	• Annual workforce plans that demonstrate evidence of ongoing workforce development • Data not currently collected

Appendix I

Proposed Minimum Data Set

Note: This is not yet an ***Agreed Data Set***[87]

The proposed Minimum Data Set (MDS) was determined by the MHCC Data Management Strategy Reference Group from the Comprehensive Data Set (CDS) that was developed by the DMS Minimum Data Set Working Group, as at 25 June 2010. The MDS Working Group compared the existing data collection sets, and found a set of fields that is a common requirement of the majority of funders. This area of overlap is considered to be essential, and forms the basis for the proposed Minimum Data Set for the CMO sector.

	Data Elements	METeOR ID Number	Rationale for proposed MDS Data Elements
	Client Identification		
2.	Client: Gender	New	• Data item will record: Male; Female; Intersex/Indeterminate; Transgender; Not stated; Not specified • Due to sensitivity to client preferences Gender is the preferred term to 'Sex' as recorded in METeOR ID 287316 Person-Sex • Social identification of a person and self-reported • FAHCSIA (PHAMS program) utilize this terminology to define client-identified gender
3.	Client: Date of Birth	287007	NHDD Definition: The date of birth of the person. • Age changes whereas date of birth is input once.

---

[87] While these data sets are aligned with the current data requirements of the major funders, a process of achieving agreement with Government funders will be undertaken in Phase 2 of the Data Management Strategy. As the largest funder in NSW, MHCC continues to work with NSW Health to reach agreement on the Minimum and Comprehensive Data Sets so that CMOs can be assured of meeting all data reporting requirements. MHCC hopes to release an addendum to this report with minor corrections and/or adjustments when an Agreed Data Set is established. Reaching agreement with other major funders of CMOs is on the agenda of the Data Management Strategy.

	Data Elements	METeOR ID Number	Rationale for proposed MDS Data Elements
			• Date of birth also assists with identification of clients with common surnames e.g. Ng; Smith • Age can be automated once date of birth is entered. • If date of birth is not known or cannot be obtained provision should be made to estimate age. • Age is calculated automatically. • Estimated date of birth is acceptable and should be flagged (a date accuracy indicator). • METeOR ID 303794 Person - Age, total years is not adequate
4.	Residential Postcode	287224	NHDD Definition: The numeric descriptor for a postal delivery area, aligned with locality, suburb or place for the address of a person.
5.	Aboriginal Status	Adaptation 291036	Adaptation METeOR ID 291036 Indigenous Status – Definition: Whether a person identifies as being of Aboriginal or Torres Strait Islander origin, as represented by a code. This is in accord with the first two of three components of the Commonwealth definition. • Use of the two terms Aboriginal Status and Torres Strait Islander Status separately and instead of the one word Indigenous • Respectful and validating of the first people of Australia • Definition to include title 'Australian Aboriginal…' • Records: Yes / No / Not known
6.	Torres Strait Islander Status	Adaptation 291036	Adaptation METeOR ID 291036 - Indigenous Status • Use of the two terms Aboriginal Status and Torres Strait Islander Status separately and instead of Indigenous • Respectful and validating of the first people of Australia • Records: Yes / No / Not known

	Data Elements	METeOR ID Number	Rationale for proposed MDS Data Elements
7.	Country of Birth	370943	NHDD Definition: The country in which the person was born, as represented by a code.
8.	Main Language other than English spoken at Home	304133	NHDD Definition: The language reported by a person as the main language other than English spoken by that person in his/her home (or most recent private residential setting occupied by the person) to communicate with other residents of the home or setting and regular visitors, as represented by a code.
	Client Characteristics		
9.	Referral Receipt Date	270005	NHDD Definition: The date on which an agency receives a client referral from another party.
10.	Referral Source	297469	NCSDD Definition: The person or agency responsible for the referral of a client to a service provider agency, as represented by a code.
11.	Accommodation Type	270088	NHDD Definition: The type of accommodation setting in which a person usually lives/lived, as represented by a code. • Some funded program/service types such as HASI need to report on accommodation at time of application including tenancy risk factors
12.	Living Arrangement	270385	NCSDD Definition: Whether a person usually resides alone or with others, as represented by a code.
13.	Children under 16 years living in Household	New	• In line with the NSW Government's 'Keep them Safe: A shared approach to child wellbeing' • Records: Yes / No
14.	Children under 16 years Not living in Household	New	• In line with the NSW Government's 'Keep them Safe: A shared approach to child wellbeing' • Records: Yes / No
15.	Primary Carer Nominated	Adaptation	NHDD Definition: Whether a person has an informal carer, as represented by a

	Data Elements	METeOR ID Number	Rationale for proposed MDS Data Elements
		320939	code. • Identifying a significant family or other relationship, e.g. legal guardian; parent; spouse if the relationship is close and enduring; a close relative or friend, provides a holistic approach to the services provided and identifies other avenues of support within the client's life.
16.	Principal Documented Diagnosis	Adaptation 391326	Adaptation of METeOR ID 391326 Episode of care - Principle Diagnosis Addition of word – Documented. NHDD Definition: • Diagnosis may vary over time, with different health assessments and health professionals. • This addition also supports the validity of the client's perceived diagnosis
17.	Additional Mental Health Diagnosis	New	• It is common for people to have more than one mental health problem.
18.	Additional Other Diagnosis	Adaptation 391322	Adaptation of METeOR ID 391322 Episode of Care – Additional diagnosis, code NHDD Definition: A condition or complaint either coexisting with the principal diagnosis or arising during the episode of admitted patient care, episode of residential care or attendance at a health care establishment, as represented by a code. • It is common for people to have a number of health-related problems • Diagnosis may vary over time with different health assessments
19.	Additional Comorbidity Factor	New	• This is relevant where two or more coexisting conditions are impacting on an individual's ability to function to potential. These conditions may not involve a diagnosis. • For example: Alcohol & Drug Use; Acquired Brain Injury; Intellectual Disability; Physical Health Impairment; Ageing issues
20.	Activity and Participation in	320125	NHDD Definition: The life area in which a person participates or undertakes

	Data Elements	METeOR ID Number	Rationale for proposed MDS Data Elements
	Life Area		activities, as represented by a code. The activities and participation codes are a neutral list that cover the full range of life areas in which a person can be involved. The domains can be used to record positive or neutral experience of functioning as well as limitations and restrictions.
21.	Level of Difficulty with Activities in Life Areas	320120	NHDD Definition: The level of difficulty a person has in performing the tasks and actions involved in specified life areas, as represented by a code. This metadata item contributes to the definition of the concept of Disability and gives an indication of the experience of disability for a person.
	Participation / Program	**Use**	
22.	Individual Assessment Date	New	• Date of assessment with client to determine eligibility • Assists with determining waiting time between individual assessment date and program entry date
23.	Service Start Date	338558	NCSDD Definition: The date on which a service episode commenced
24.	Service End Date	270160	NCSDD Definition: The date on which a service episode was completed
25.	Hours of Service per Contact - Direct	New	• Actual hours of service per contact entered by staff • Hours of direct client services delivered • Collation of contact hours will match against funding agreement
26.	Hours of Service per Contact - Indirect	New	• Hours of indirect client services provided • Information collected may assist with identifying variance • Collation of contact hours will match against funding agreement
27.	Service / Other Agency Use on Entry	New	• Determines other support services being accessed by the client at time of program entry • Also useful for identifying gaps and improved care coordination

	Data Elements	METeOR ID Number	Rationale for proposed MDS Data Elements
			- State and locality specific - Includes: Peer Support Group or Activity; GP; Psychiatrist; NA/AA; Community Mental Health service; Clubhouse; Alcohol & Other Drugs; Inpatient Unit; Depot Clinic; Psychologist; Carer Support Group; Commonwealth Carelink; HACC service; Aged Care; COPMI; Youth service; Aboriginal or Torres Strait Islander service/group; Culturally-specific support group; Counselling service; CMO group; Other government agency; Complementary therapy centre; Other
	Outcome Measures		
28.	Outcome Measures - as per CMO practice	New	- A snapshot of sector-wide outcome measures that are evidence-based are provided - Examples of tools commonly used for assessment of client needs, monitoring and recovery processes, and funding requirements - Recommend use of K10+ and CANSAS - Outcome measures can be added or hidden depending on CMO practice - It is expected that each CMO will have the required license for use, unless the measures are in the public domain
	Organisation & Program	**Identification**	**/ Characteristics**
29.	Program Name Type	288937	NHDD Definition: A classification that enables differentiation between recorded names for an establishment, agency or organisation, as represented by a code.
30.	Funding Source/s	New	- Collection of data will assist with the identification of the diverse CMO funding sources in NSW and Australia
31.	Program Suburb	290059	NHDD Definition: The full name of the general locality containing the specific address of an organisation, as represented by text.

	Data Elements	METeOR ID Number	Rationale for proposed MDS Data Elements
32.	Program Postcode	290064	NHDD Definition: The numeric descriptor for a postal delivery area, aligned with locality, suburb or place for the address of an organisation, represented by a code.
33.	Service Type	New	• Identifies the type of service being provided • Recognises the diversity of services provided by CMOs
	Workforce Summary		
34.	Workforce FTE	New	• CMOs full time equivalent paid staff comprising full time, part time and casual staff members • Data is not currently collected • Collection of this data would be in line with evidence-based practice
35.	Age Range - Workforce	Adaptation 290540	Adaptation of METeOR ID 290540 Person – age range, code. • To be adapted for Workforce • Assists with identification and planning to address ageing workforce • Data not currently collected • Age ranges would be consistent with the standard 10 year ranges recommended by the ABS

Legend:

METeOR ID number is for data elements from the National Health Data Dictionary unless stated otherwise.

NHDD	National Health Data Dictionary

NCSDD	National Community Services Data Dictionary
New	New data element
Adaptation	Adaption of an existing data dictionary data element

Appendix J

Data Tables from MHCC Sector Mapping Project

The majority of CMOs funded to provide mental health services (Types 1 and 2) are also providing other types of services. The data shows a large number of previously unidentified CMOs (Type 3) that are not funded to provide mental health services, but are nevertheless modifying programs to meet the needs of people living with mental health problems.

Size of Mental Health CMOs

Table 11 shows the size and number of CMOs that participated in the Sector Mapping Survey with Table 12 identifying the profile of CMO Types who responded. Note: peak bodies have been removed.

Table 11: Size and Number of Mental Health CMOs in NSW

Size of CMO	CMO Type 1	CMO Type 2	CMO Type 3	Total
Non-frontline / volunteer based = 0 FTE	4	26	45	75
Small = 1 – 4 FTE	6	25	12	43
Medium = 5 – 19 FTE	5	20	13	38
Large = 20+ FTE	15	21	7	43
Total	**30**	**92**	**77**	**199**
FTE = Full time equivalent staff positions	5 Type 1 CMOs did not answer this question	10 Type 2 CMOs did not answer this question	33 Type 3 CMOs did not answer this question	**247**

Table 12: ***Profile of CMOs Responding to Survey***

Type of CMO	Number of CMOs responding to survey	Percentage of all respondents
Type 1 – CMOs providing mental health services only	35	14%
Type 2 – CMOs providing mental health and other services	102	41%
Type 3 – CMOs that do not provide mental health services, but provide support for people with mental illness	110	45%
Total	**247**	

Data Systems used by CMOs

CMOs were surveyed about the data systems used to collect information.

Table 13 shows that the majority of CMOs working in mental health use computer systems for all or some data collection, but that a significant percentage of CMOs use only paper-based or manual systems – Table 14.

Table 13: ***Data systems used by CMOs: Computerisation***

Percentage of use of specific data systems for administration			
Computerised	**Computerised and manual**	**Manual/ paper-based**	**Neither system**
18%	60%	13%	9%

Table 14: ***Data systems used by CMOs: No administrative system***

Percentage of CMOs with <u>no</u> data system for administration	
Type 1 – CMOs providing mental health services only	3%
Type 2 – CMOs providing mental health and other services	2%
Type 3 – CMOs that do not provide mental health services, but provide support for people with mental illness	18%

Type of Data Collected

CMOs were also asked about the type of data collected. Table 15 (below) shows the proportion of CMOs currently collecting specific data. It indicates that there is a lack of consistency in the type of data universally collected by CMOs working in mental health in NSW. Note the term 'client' refers to either consumers or carers, and the term 'consumer' relates specifically to people with mental health issues.

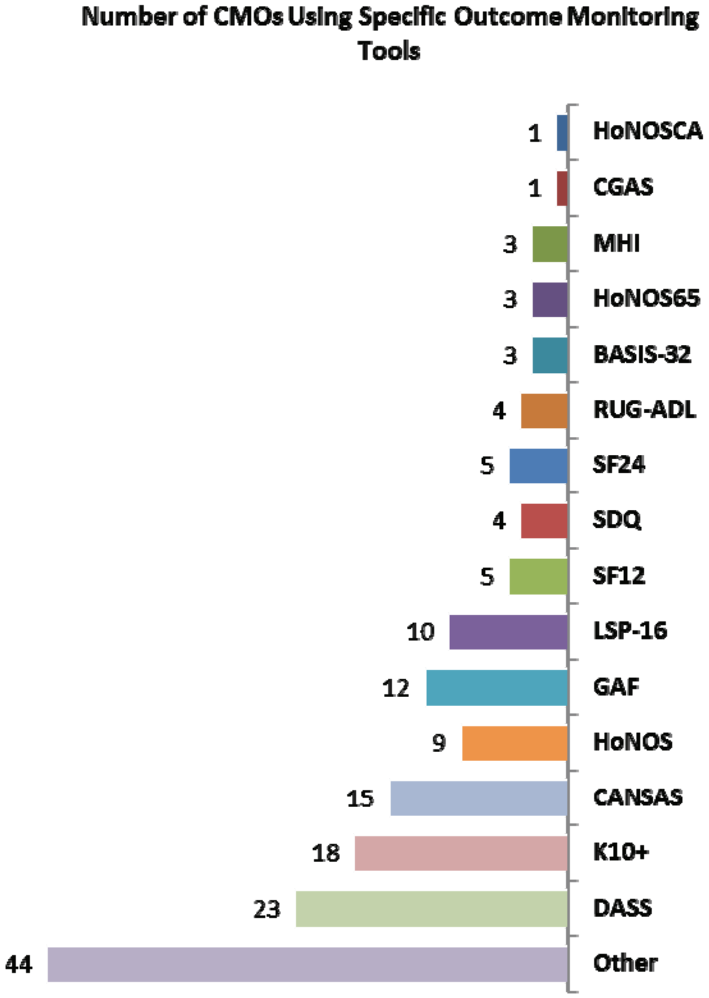
Table 15: Proportion of CMOs collecting specific data

Type of data	Percentage of CMOs collecting data type
Client personal information	85%
Referral sources	82%
Type of assistance provided	81%
Mental health diagnosis	75%
Client circumstances	73%
Client progress monitoring	70%
Consumer functional status	63%
Client exit details	60%
Amount of time assistance provided	59%
Other data	49%

Outcome measures

CMOs were asked to identify the specific outcome measurement tools used. On average, Type 1 CMOs use **3** tools and Type 2 use **2** tools.

The following graph below shows the number of CMOs using specific outcome measurement tools. It indicates that K10+ and DASS are the preferred outcome measurement tools, but also shows the lack of standardised collection of outcome monitoring data in the CMO mental health sector.



The 44 ‘Other’ outcome monitor tools include:

- Department of Employment & Workplace Relations IT platform for employment outcomes (EA3000)
- Beck Depression Inventory (BDI)
- Beck Scale for Suicidal Ideation (BSI)
- Brief Treatment Outcome Measure (AOD)
- Satisfaction with Life Scale
- Variety of other tools including some internally developed measures.

Geographic Reach of CMO Programs

318 programs reported in the mapping survey fell within the seven core service areas. These are referred to as ‘core’ programs.

The numbers of programs reported in each core service area were:

- Employment & Education (n=91)
- Accommodation Support & Outreach (n=56)
- Self-help & Peer Support (n=49)
- Helpline & Counselling Services (n=46)
- Leisure & Recreation (n=32)
- Information, Advocacy & Promotion (n=23)
- Family & Carers (n=21)

NSW Health is divided into eight Area Health Services (AHS); four contain predominantly rural populations and four contain predominantly urban populations. A large number of CMOs run multiple programs, in a number of different Area Health Services.

Rural	**Urban**
Greater Southern AHS	Northern Sydney / Central Coast AHS
Greater Western AHS	South Eastern Sydney / Illawarra AHS
Hunter / New England AHS	Sydney South West AHS
North Coast AHS	Sydney West AHS

Analysis of core programs for each Area Health Service is indicative rather than exhaustive; data relating to programs reported by organisations responding to the Mapping Survey provide the basis for the analysis. See Table 16.

The findings show that:

1. The highest number of core programs (n=76) is reported in Sydney West AHS
2. The lowest number of core programs (n=24) is reported in Greater Western AHS
3. There are more core programs reported in the four urban Area Health Service regions

Table 16: Number of Responding Core Service Programs operating in each AHS

	RURAL AHS				URBAN AHS			
CORE SERVICE	**GS**	**GW**	**HNE**	**NC**	**NSCC**	**SESI**	**SSW**	**SW**
Accommodation Support & Outreach	9	7	9	10	11	12	17	13
Employment & Education	12	9	13	23	15	19	19	19
Family & Carers	4	2	2	0	6	3	4	5
Helpline & Counselling services	1	2	13	10	7	8	9	7
Leisure & Recreation	7	0	2	2	0	7	5	12
Information, Advocacy & Promotion	2	3	0	1	1	2	3	5
Self-help & Peer Support	4	1	3	4	11	9	8	15
Total	**39**	**24**	**42**	**50**	**51**	**60**	**65**	**76**

Note: *Programs reported as operating in more than one AHS are counted in each AHS*

🟥 AHS with lowest reported programs 🟩 AHS with highest reported programs

Appendix K

Database Evaluation Ranking

The working group directly contacted the database developers, organised appointments and advised the reason and purpose of the demonstration to recommend to the CMO mental health sector. Individual group members were assigned databases and asked to undertake the completion of the criteria matrix and gather information at the demonstration. Additional contact occurred at a later date if further information was required. The working group had the opportunity to see a working version of all but one of the databases, and considered the maturity of development of the programming, and the degree to which the database was able to meet the level of completeness and flexibility required by the mental health CMO sector.

All the databases were considered on whether they met all the requirements of the criteria matrix and mental health CMO sector requirements, and if they needed development.

Two databases, based on the *NoCode 360* platform were developed by organisations represented on the working group using NGO Infrastructure Grants Program funds. The working group viewed demonstrations of each of the databases, which allowed assessment of the maturity of development of the programming and the degree to which the database was able to meet the level of completeness and flexibility required by the CMO sector.

A number of databases did not meet a number of the criteria. Both of the *NoCode 360* databases, *Amanda* and *Insite*, were not adequately developed (as at January 2010 the database platform is a pre-release version) to be useful across a sector as broad and large as the member base of MHCC. These databases had many omissions when measured against the criteria matrix, and at the current stage of development, would require major development and thus cost to bring them up to the required level. The representatives of the two organisations that developed these databases advised that the support might not be available for the level of technological development needed.

The *Gemma* and *Dewacorp* databases also did not incorporate a number of matrix elements that the group considered to be essential for the needs of the sector. From the demonstration it was determined that CIMS*ability* required further development to meet the requirements of mental health CMOs. The developers of the *Medical Director* database denied a review of the database advising that the database was not appropriate for use by CMOs as it is for Australian GPs and Specialists. These five databases were thus eliminated from further consideration.

A pertinent issue when assessing the databases was the consideration of cost, in particular those systems that charged for each user in the organisation rather than each concurrent user. This is an issue for the CMO sector in which there is often a large pool of casual staff. Though meeting a number of criteria *Recordbase* was unable at the time to provide specific costs per concurrent user to the group.

Similarly, whilst they met many of the criteria set out in the matrix *MACSIMS* and *CSnet*® were considered to be cost prohibitive due to the ‘per user’ cost figures supplied by the companies.

Corelogic *Frameworki* is a UK-based product that The Schizophrenia Fellowship of NSW has procured, with adaptation to Australian mental health standards and input being undertaken. The security of *Frameworki* was deemed efficient and effective with all the criteria being met, and the model proposed for MHCC as an umbrella organisation was sound. However the working group considered *Frameworki* might be less cost-effective as it is a case management tool with few of the other functions that *Carelink*+ has, for example the HR module. Though *Carelink*+ is not a web-based application it can be remotely accessed using other systems such as Citrix and Terminal Services. The advantage of this over web-based is CMO retainment of full control of own data.

As mentioned, the group had an opportunity to see a working version of all but one of the 11 databases. One area that the matrix did not capture was the maturity of development and completeness of a database for use by the broad range of NGOs who are members of MHCC. This completeness is an important requirement when the member base is so varied and cost-constrained as it means that the range of elements already contained in the developed program are able to fit a range of diverse requirements without costly further development. It was also necessary that the database meet the needs of the mental health sector specifically, as many of the databases reviewed were developed for the disability sector.

Appendix L

Definition of Terms

The following terms relate to this report and include commonly used terms in Australian data collections in the human services. The data related terms are extracted from the Australian Institute of Health and Welfare's *Guide to Data Development*, 2007 and other sources with additional explanation where required.

Benchmarking

Benchmarking is a structured approach to provide a standard for measuring and comparing processes to other comparable processes. Benchmarking is a core component of continuous quality initiatives.

Casemix

A means of classifying hospital patients to provide a common basis for comparing cost-effectiveness and quality of care across hospitals.

Clearinghouse

A clearinghouse is an institution that coordinates information interchange. An example is the Australian Domestic and Family Violence Clearinghouse, which is a national organisation, providing high quality information about domestic and family violence issues and practice.

Client

A client of a service is a person who accesses community services, also referred to as a consumer or service user. In the mental health sector, the term client may refer to a person with mental illness and/ or their carer.

Comorbidity

Comorbidity refers to people living with a mental illness, who have other significant health issues, for example substance abuse.

Community-Managed Organisations (CMOs)

Community-Managed Organisations provide a broad range of services and programs for community members with a common need or interest. CMOs are usually governed by an elected Board of Directors, and are funded by one or more sources, including government and/ or corporate grants, and donations/ bequests from sponsors. Other terms used for CMOs include non-government organisations (NGOs), Not-for-Profit, and Third Sector.

Comprehensive Data Set

The DMS Comprehensive Data Set has been developed to capture the data collection of diverse CMOs working in mental health in NSW. The comments applied to each metadata item are designed to ensure that each definition is clear, concise, comprehensive and provides sufficient information to ensure that all those who collect, provide, analyse and use the data are able to understand its meaning.

Consumer

In the mental health sector a consumer refers to a person living with a mental illness or mental health problem.

Data

Data is the ‘representations of real world facts, concepts or instructions in a formalised manner suitable for communication, interpretation or processing by human beings or by automatic means’ (Standards Australia 2005 in AIHW 2007:6).

Data development

The process of identifying the information needs of an industry, business or service, producing data standards that support standardised and consistent data collection and usage. It starts with a business’s need for information (AIHW, 2007:10), not with funder requirements. It ends with the building of a data set.

Data element

An item or unit of data ‘for which the definition, identification, representation and administration are identified by means of a set of fields or attributes’ — ‘each data element represents a basic unit of identifiable and definable data of interest’ (AIHW 2007:8)

Data quality

Data quality refers to the reliability and consistency of data that is measuring the same elements over time.

Data set

A data set is a data collection. For example, the *NSW Minimum Data Set for Drug and Alcohol Treatment Services* is an agreed minimal data collection for alcohol and other drugs sector.

Data Standards

Australian standards for data collections in the human services compiled through the Australian Institute of Health and Welfare and contained within the National Health Data Dictionary (NHDD), the National Community Services Data Dictionary (NCSDD) and the National Housing Assistance Data Dictionary (NHADD).

Database

A collection of information organised in such a way that a computer program can quickly find desired pieces of data. A database is an electronic filing system.

Data dictionary

A data dictionary names and defines data items within a business and technical use context. It describes each item and determines where it fits within the data model. A data dictionary is used so that information can be correctly recorded within the system and retrieved.

Data system

A data system refers to all components of information identification, collection, storage and use, such as the technology used, including collection tools and formats, paper and electronic databases, computer hardware and software. It also refers to the processes used for obtaining information and analysing it, and for reporting and research.

e-Health

An Australian government project to enhance the use of electronic systems to manage health services, treatments and reviews.

Family Wellbeing Program

A program has been developed around the key understandings and skills that help Aboriginal and Torres Strait Islander people to heal and become leaders in their communities. Many people have been directly affected by policies of the Stolen Generation, experiencing substantial social and emotional trauma linked to severe grief and loss. The content is enhanced with additional resources and skills building exercises from mainstream and Eastern philosophies to enhance feelings of calmness and inner peace. The Growth and Empowerment Measure (GEM) has been developed as a result.

Firewall

A firewall is the use of computer hardware and software to block access between an Internet network and the rest of the Internet. A Firewall protects the computer and its information from unauthorised access by hackers or vandals who wish to steal information or damage the computer system.

Hardware

Computer equipment that can include the Central Processing Unit (CPU), monitor, keyboard, printer, external modem or CD drive, etc.

Information

Refers to data when used and interpreted.

Information system

Refers to electronic systems to house data, including web portal based systems.

Interface

A common boundary shared by two devices, or by a person and a device, across which data or information flows, e.g. the screen of a computer. Computer software that links a computer with another device, or the set of commands, messages, images, and other features allowing communication between a computer and the user.

Medical Record Number (MRN)

A medical record is an Area Health Service's documented account of a patient's illness and treatment during each hospital stay or visit and serves as a basis for review, study and evaluation of care given to the patient. It also provides a means of communication regarding episodes of illness for all health care personnel and should serve as a basis of planning continuity of patient care.[88]

Metadata

Metadata describes how, when and by whom a particular set of data was collected, and how the data is formatted. Metadata is essential for understanding information stored in data warehouses.

Minimum Data Set

The proposed Minimum Data Set is a minimum set of data elements that have been agreed to by CMOs working in mental health in NSW as suggestions for mandatory collection and reporting.

National Minimum Data Set

A National Minimum Data Set (NMDS) is a minimum set of data elements agreed for mandatory collection and reporting at a national level. A National Minimum Data Set may include data elements that are also included in another National Minimum Data Sets.

A National Minimum Data Set is contingent upon a national agreement to collect uniform data and to supply it as part of the national collection, but does not preclude agencies and service providers from collecting additional data to meet their own specific needs. Key words that describe a National Minimum Data Set are:

---

[88] NSW Health, Guidelines for the Recovery and Resources Services Program (RRSP) Data Collection System May 2010

- Minimum - Standards - Agreement - Collection - Reporting[89]

Privacy and Privacy Acts

The type of privacy covered by the federal *Privacy Act 1998* and the Office of the Privacy Commissioner is the protection of people's personal information. Other types of privacy can include territorial privacy and physical or bodily privacy and privacy of communications. People regard health information as one of the most sensitive types of personal information. For this reason, the Privacy Act provides extra protections around the handling of health information. For example, an organisation needs an individual's consent before they can collect their health information.

The *Health Records and Information Privacy Act 2002* (or HRIP Act) protects the privacy of health information in NSW. The HRIP Act governs the handling of health information in both the public and private sectors in NSW.

Server

A server is any computer that stores information and makes it available to outside users. It is generally more powerful than a standard desktop PC and can be dedicated to specific tasks, such as a print server, and acts as a resource for other desktop computers on the network.

Software

Software is a general term for the various kinds of programs used to operate computers and related devices.

The Gender Centre

The Gender Centre offers support, referrals, education and training to people with gender issues, their partners, families and friends in NSW and to organisations and service providers. www.gendercentre.org.au

Third Sector

The third sector refers to a group of community-based organisations that are separate to government and business. These organisations are also known as CMOs, NGOs or not-for-profit organisations.

Transgender

Transgender is a term used to describe anyone who lives or wishes to live as a member of the opposite gender to his or her birth gender. It may also encompass,

---

[89] Australian Institute of Health and Welfare, http://www.aihw.gov.au/datadevelopment/faqs.cfm#what_is_a_nmds

under a broad definition, anyone who presents or behaves ambiguously in relation to commonly accepted male ⁄ female gender expectations.

Unique identifier

A unique identifier is the allocation of a number or code to each person, so that information can be tracked or monitored. For example, the Unique Patient Identifier for medical services

Web Server

Program running on a computer connected to the Internet. It is designed to deliver web pages to other computers and to wait for new requests for information to be made.

Appendix M

Acronyms

ACHS	Australian Council on Healthcare Standards
ADHC	Ageing Disability & Home Care Department NSW
AHS	Area Health Service
AIHW	Australian Institute of Health and Welfare
APQ6	Activity and Participation Questionnaire
AUDIT	Alcohol Use Disorders Identification Test
BASIS-32	Behaviour and Symptom Identification Scale – 32 items BASIS-24 Behaviour and Symptom Identification Scale – 24 items
CACOM	Centre for Australian Community Organisations and Management
CALD	Cultural and linguistically diverse
CANSAS	Camberwell Assessment of Need Short Appraisal Schedule: CAN-C Camberwell Assessment of Need – clinical version CANDID Camberwell Assessment of Need – for adults with developmental and intellectual disabilities CANE Camberwell Assessment of Need – for elderly persons CANFOR Camberwell Assessment of Need – forensic version
CDS	Comprehensive Data Set
CEO	Chief Executive Officer
CEO-NGO	Consumer Evaluation of NGOs
CGAS	Children's Global Assessment Scale
CMOs	Community-Managed Organisations
CSnet	Consulting company for network management
DASS	Depression Anxiety Stress Scales
DAST	Drug Abuse Screening Test
DMS	Data Management Strategy - MHCC project
DOHA	Commonwealth Department of Health and Ageing
DSM IV	Diagnostic and Statistical Manual for Mental Health Disorders version 4, American Psychiatric Association

FIHS	Factors Influencing Health Status
FOC	Focus of Care scale
FTE	Full time equivalent staffing levels
GAF	Global Assessment of Functioning Scale
GDP	Gross Domestic Product
GEM	Growth and Empowerment Measure
HACC	Home and Community Care, Commonwealth program
HADS	ADHC Software (HADS Version 2.0.0c) for HACC MDS
HASI	Housing and Accommodation Support Initiative, NSW Health
HoNOS	Health of the Nation Outcome Scale (Adult), including: HoNOS65+ Health of the Nation Outcome Scale (over 65 years) HoNOSCA Health of the Nation Outcome Scale (children)
HSNet	Health Services Network - online health information
ICD10-AM	International Classification of Disease Revision 10 - Australian Modification, World Health Organisation
ICT	Information and Communication Technology
IGP	Infrastructure Grant Program
InforMH	NSW Health's Mental Health Information Unit
ISO	International Organisation for Standardization
IT	Information Technology
K10+	Kessler Psychological Distress Scale – 10 items K10+LM Kessler Psychological Distress Scale K10-L3D Kessler Psychological Distress Scale
KPIs	Key Performance Indicators
LSP-16	Life Skills Profile 16 items LSP-39 - Life Skills Profile 39 items
MDS	Minimum Data Set
METeOR	Australian Health and Community Services Data Register
MHCC	Mental Health Coordinating Council NSW
MH-COPES	Mental Health Consumer Perceptions and Experiences of Services

MHDAIS	Mental Health and Drug and Alcohol Information Sub-Committee, of the Mental Health and Drug and Alcohol Program Councils
MHDAO	Mental Health and Drug and Alcohol Office, NSW Health
MH-OAT	Mental Health Outcomes and Assessment Tools
MRN	Medical Record Number
NADA	Network of Alcohol and Drug Agencies
NCOSS	New South Wales Council of Social Services
NGOs	Non-government organisations
NSW	New South Wales
NSW CAG	NSW Consumer Advisory Group
NZ	New Zealand
PCs	Personal computers
PWI-A	Personal Wellbeing Index - Australia
QICSA	Quality Improvement & Community Services Accreditation
QMS	Quality Management Services
RRSP	Recovery and Resource Services Program, NSW Health
RTO	Registered Training Organisation
RUG-ADL	Resource Utilisation Group – Activities of Daily Living
SDQ	Strengths and Difficulties Questionnaires
SF12	Short Form 12 and 24
STORI	Stages of Recovery Inventory – under development
SWLS	Satisfaction with Life Scale - 18 items
TAS	Therapeutic Alliance Scale
UK	United Kingdom
USA	United States of America
WHOQoL	World Health Organisation (WHO) Quality of Life

Appendix N

References

Adelman, S., Rehm, C., & Tannenbaum, A., *What is considered data management best practice?* Information Management Online, 8 January 2004

Andresen, R., Caputi, P., & Oades, L, *Stages of recovery instrument: development of a measure of recover from serious mental illness,* Australian and New Zealand Journal of Psychiatry 2006, Vol. 40

ARTD, *Guidelines for Families and Carers Mental Health Program: Monitoring and Reporting System,* Version 2, January 2009

Attorney General's Department, *National Compact Consultation Paper: Engage. A new relationship between the Australian Government and the Third Sector,* 2009

Australian Government Productivity Commission, *Contribution of the Not-For-Profit Sector,* Research Report, Canberra, January 2010

Australian Health Minister's Advisory Council, *Healthcare Identifiers and Privacy: Discussion paper on proposals for legislative support,* July 2009

Australian Institute of Health and Welfare, *Home and Community Care (HACC) Program: National Minimum Data Set. HACC Data Dictionary, Version 1,* May 1998

Australian Institute of Health and Welfare, *Specialised mental health organisations: Counselling services grants to non-government organisations,* 8 December 2004

Australian Institute of Health and Welfare, *Cutting the red tape: Preliminary paper detailing the problem of multiple entry and reporting by service providers,* November 2006

Australian Institute of Health and Welfare, *A guide to data development*, 2007

Australian Institute of Health and Welfare, *Alcohol and Other Drug Treatment Services National Minimum Data Set, National Health Data Dictionary*, version 12, 2003

Australian Public Service Commission, *Working with stakeholders and moving to more inclusive government 2007-08*

Australian Public Service Commission, *Policy Implementation through Devolved Government*, 2009

Australian Public Service Commission, *Smarter Policy: Choosing policy instruments and working with others to influence behaviour*, 2009

Briggs, L., *Contemporary Government Challenges: Delivering performance and accountability and the intersections with 'wicked' policy problems,* paper for Meeting of the International Society for the Systems Services (ISSS), Plenary Session, 15 July 2009

Burgess, P., Pirkis, J. *Case Complexity adjustment and Mental Health Outcomes: Conceptual Issues.* Australian Mental Health Outcomes Classification Network, In National Mental Health Performance Subcommittee Agenda Paper 12, 2-3 April 2009

Centrelink, 2003, *A Guide to Ethnic Naming Practices,* Australian Government

Clarke, S., Oades, L. G., Crowe, T. P., Deane, F. P., *Collaborative Goal Technology: Theory and Practice,* University of Wollongong, Psychiatric Rehabilitation Journal, Fall 2006, Vol. 30 No. 2

Commonwealth of Australia, *The Development of the Fourth National Mental Health Plan: A Discussion Paper,* February 2009

Commonwealth of Australia, *Fourth National Mental Health Plan 2009-2014*, 2009

Commonwealth Department of Broadband, *Communication and the Digital Economy: Australia's Digital Economy: Future Directions,* 2009

Commonwealth Department of Health and Ageing, *Ways Forward: National Aboriginal and Torres Strait Islander Mental Health Policy: National Consulting Report.* Chapter 16: Data and Information Systems, February 1995

Commonwealth Department of Health and Ageing, *Mental Health Information Development: Mental Health National Outcomes and Casemix Collection: Overview of Clinician-rated and Consumer Self reported measures*, Version 1.50. December 2003

Commonwealth Department of Health and Ageing, *Key Performance Indicators for Australian Public Mental Health Services: Report of Performance Indicator Drafting Group*. Information Strategy Committee, Discussion Paper No. 5, November 2004

Commonwealth Department of Health and Ageing, *Mental Health Information Development: National Mental Health Information Priorities,* 2nd Edition, June 2005

Commonwealth Department of Health and Ageing, *National Action to Improve the Quality of Mental Health Services: A Summary of Activity 1992-2003.* Information Strategy Committee, Discussion Paper No. 6, 2005

Commonwealth Department of Health and Ageing, *National Outcomes and Casemix Collection: Programs,* 19 January 2009

Commonwealth Department of Health and Ageing, *Review of Health Technology Assessment in Australia: A Discussion Paper,* 2009

Consumer Centred eHealth Coalition www.consumerehealth.org

Consumer Health Forum of Australia, *Chronic Conditions Self Management 2008-10 Project: National Consumer Representative and Stakeholder Planning Workshop Report,* August 2008

Consumer Outcomes in Mental Health Western Australia www.comhwa.health.wa.gov.au

Craze Lateral Solutions, *Discussion Paper: Scoping Study to Inform the Establishment of a New Peak National Mental Health Consumer Organisation,* November 2009

Gender Centre Inc. NSW, *General Information Kit for Services,* July 2008 www.gendercentre.org.au

Gershon, Sir P., *Review of the Australian Government's Use of Information and Communication Technology (ICT),* Publication Summary, October 2008

Harding, E., *Privacy Impact Assessment and Commentary on the Mental Health Information Project for New Zealand Health Information Service,* February 1999

Haswell-Elkins, M., Hunter, E., Wargent, R., Hall, B., O'Higgins, C., & West, R, 2009, *Protocols for the delivery of social and emotional wellbeing and mental health services in Indigenous communities: Guidelines for health workers, clinicians, consumers and carers*, First Edition, Australian Integrated Mental Health Initiative, Indigenous Stream in North Queensland for Northern Area Health Services, Queensland Health, Cairns

Heyler, K., Tobias, G., Traver, T., Neami, *Lessons learned from using Routine Outcome Monitoring in a Psychiatric Disability and Rehabilitation and Support Service,* paper presented at 2020 Vision: Melbourne Conference 2007, and TheMHS Conference, Sydney

Hillier, L., Turner, A., Mitchell, A., 2005, *writing themselves in again: 6 years on. The 2nd national report on the sexuality, health & well-being of same sex attracted young people in Australia*, La Trobe University, Australian Research Centre in Sex, Health & Society (ARCSHS), Faculty of Health Sciences, Monograph series no. 50, Melbourne Victoria

Ilems, L., *Transparency, Accountability and Performance Measurement*, ProBono Australia, 31 August 2009

Kendrick, M., *Self direction in services and the emerging safeguarding of advocacy challenges that may arise,* 9 June 2005 www.kendrickconsulting.org/pubs.asp?pid=0&ctid=15&cid=0&tr=SITEMENU

Kimberly, J., Cook, J., *Organisational Measurement and the Implementation of Innovations in Mental Health Services*, Admin Policy Mental Health, 2008, Vol. 35, pp11-20

Lasa Information Systems, *Staff Responsibility for Information Technology Support* www.ictknowledgebase.org.uk

Lasa Information Systems, *So what is a circuit rider?* Lasa Circuit Riders 2.0 www.ictknowledgebase.org.uk

Lasa Information Systems, *ICT Health check,* www.ictknowledgebase.org.uk

Lasa Information Systems, *On the road again: Reflections on Lasa's Circuit Rider Project 2002-04,* United Kingdom

Leginski, W. A., Croze, C., Driggers, J., Kamis-Gould, E., Namerow, M. J., Patton, R. E., Wilson, N. Z., & Wurster, C. R., 1989, *Data standards for mental health decision support systems,* Series FN No. 10, Rockville, MD: U.S. Department of Health and Human Services

Malone, J., *Mental Health Computers: The reframing of clinical information technology in mental health services in NSW,* Research Paper (unpublished), 1990

Marshall, B., *Evaluation Skills Development Project: Evaluating Mental Wellbeing and Social Connectedness,* School of Health and Social Development, Deakin University, PowerPoint presentation undated

Mental Health Coordinating Council and NSW Council for Social Services, *Joint Submission to Senate Community Affairs Committee Inquiry into Mental Health Services in Australia,* Sydney NSW, August 2007

Mental Health Coordinating Council, *The NSW Community Managed Mental Health Sector: Report of the New South Wales Community Managed Organisation (CMO) Sector Mapping Project*, 2010

Mental Health Coordinating Council, *Mental Health Recovery – Philosophy into Practice: A Workforce Development Guide*, 2008

Mental Health Coordinating Council, *NGO Development Strategy: Mental Health 2004-2007: Final Report,* Sydney NSW, January 2008

Mental Health Coordinating Council, *Mapping the Difference We Make: Discussion Paper,* Executive Summary, Sydney NSW August 2006

Mental Health Coordinating Council, *Social Inclusion: Its importance to mental health,* Sydney NSW, June 2007

Mental Health Coordinating Council, *NGO Information Strategy: Understanding Activity and Outcomes in NGOs providing mental health programs in NSW,* Sydney NSW April 2007

Mental Health Council of Australia, *Submission to Senate Community Affairs Committee's Inquiry into Mental Health Services in Australia,* January 2007

Mental Health Services Victoria, *Psychiatric Disability Rehabilitation and Support Services: Guidelines for Service Delivery*, Victoria February 2003

National Association of State Mental Health Program Directors, *Mental Health Recovery: What Helps and What Hinders? A National Research Project for the Development of Recovery Facilitating System Performance Indicators,* Phase II Technical Report: Development of the Recovery Oriented System Indicators (ROSI) Measures to Advance Mental Health System Transformation, 2006, New York State Office of Mental Health, USA

National Centre for Classification in Health, *ICD-10-AM*, The University of Sydney, http://nis-web.fhs.usyd.edu.au/ncch_new/2.aspx

National Centre of Mental Health Research and Workforce Development, *NgOIT Landscape Survey 2005,* New Zealand, October 2006

National E-Health Transition Authority, *Privacy Blueprint for the Individual Electronic Health Record: Report on Feedback,* 3 July 2008

National Mental Health Performance Subcommittee, *Implementation of Key Performance Indicators and Future Directions,* Agenda Paper 5, 2-3 April 2009

Neami, *Criteria for a Consumer Management Database,* 28 May 2008

Network of Alcohol and Other Drug Agencies, *NGO Drug and Alcohol and Mental Health Information Management Project: Determining the Treatment Outcomes Data Collection Set,* Sydney NSW, August 2009

Network of Alcohol and Other Drug Agencies, *Drug and Alcohol and Mental Health Information Management Project: Baseline Evaluation Report,* EJD Consulting and Associates, September 2009

New Zealand Ministry of Health, *National Mental Health Information Strategy 2005-10,* Wellington New Zealand, June 2005

New Zealand State Services Commission, *Promoting Government Information and Data Re-use: Background Paper,* New Zealand, December 2008

NSW Consumer Advisory Group – Mental Health Inc. and Mental Health Coordinating Council, *Literature Review on Recovery*, Developing a Recovery Oriented Service Provider Resource for Community Mental Health Organisations, August 2009, NSW

NSW Council of Social Services, *Information Technology Strategy Project: Discussion Paper,* Sydney NSW April 2007

NSW Council of Social Services, *Community Connexions: Addressing the Information and Communication Technology Needs of the NSW Human Services Sector,* Executive Summary, Sydney NSW December 2008

NSW Council of Social Services, *Towards Triple A Rated Community Services: Social and Economic Priorities for a fair and sustainable community 2009-10 State Budget,* Sydney NSW, October 2009

NSW *Family and Carer Mental Health Program,* www.health.nsw.gov.au/mhdao/fcmhp.asp

NSW Health, *Guidelines for the Recovery and Resources Services Program (RRSP) Data Collection System*, Draft, May 2010, NSW

NSW Health, *HACC Minimum Data Set Version 2: Concepts and Data Elements and Orientation Workshop for NSW Health HACC services*, NSW

NSW Health, *HASI Monitoring Form 1: Applicant Profile*, Mental Health and Drug and Alcohol Office, Version 5, 2010, NSW

NSW Health, *HASI Monitoring Form 2: Clients Receiving Support*, Mental Health and Drug and Alcohol Office, Version 5, p3, 2010

NSW Health, *Mental Health Outcomes and Assessment Statistics (MH-OAT) Data Collection: Reporting and Submission Requirements,* NSW, 21 June 2001

NSW Health, *NSW Incident Information Management System Policy,* Circular No. 2004/82, File No 04/1517, Issued 1 December 2004

NSW Health, *Data Collections: Process for Approval of New or Modified,* Policy Directive, 25 January 2005

NSW Health, *2004-05 Data Dictionary and Collection Guidelines for the NSW Minimum Data Set for Drug and Alcohol Treatment Services,* NSW, Version 4, 2005

NSW Health, *Policy Directive: Data Dictionary and Collection Requirements: NSW Minimum Data Set Drug and Alcohol Services 2005-07,* 20 February 2006

NSW Health Records and Information Privacy Act 2002 http://www.lawlink.nsw.gov.au/lawlink/privacynsw/ll_pnsw.nsf/pages/PNSW_03_hripact#1

NSW Health, *The InforMH-ant*, No. 3, 31 Sydney NSW, August 2006

NSW Health, *Community Health Information Strategy: Program Approach,* Sydney NSW March 2007

NSW Health, *Drug and Alcohol Treatment services in NSW 2005-06: Annual Report on the NSW Minimum Data Set,* Sydney NSW, 2007

NSW Health, Mental Health Drug and Alcohol Office, *NGO Information Plan: Outline,* NSW 29 July 2009

NSW Health, *NSW Health Non-Government Organisations Review – Background Information,* 2009

NSW Health, *Orientation Work Book for the NSW Health Home and Community Care Minimum Data Set,* Version 2, 2009

Pitts, M., Smith, A., Mitchell, A., Patel, S., *Private Lives: A report on the health and wellbeing of GLBTI Australians*, Gay and Lesbian Health Victoria, The Australian Research Centre in Sex, Health & Society, March 2006, Monograph series number 57, Melbourne Victoria

Primary Care Trust, *Suicide audit in Primary Care Trust localities: Data Collection Proforma,* undated

Privacy Act 1998, Federal http://www.privacy.gov.au

Psychiatric Rehabilitation Service, *Disability Support Program Evaluation,* Draft, Victoria, September 2005

Ronnau, P., Papakotsias, A., Tobias, G., Neami, *'Not for' Sector in Community Mental Health Defines itself and Strives for Quality,* Australian Journal of Primary Health, Vol. 14. No. 2. August 2008

Santhanam, R., McEwan, A., Bainbridge, R., Hunter, E., Haswell, M., et al, *Adapting the Australian Public Mental Health Performance Indicators to the Contextual Needs of a Remote Area Child and Youth Mental Health Service,* Vol. 9. No. 1. 5 February 2009

Select Committee on Mental Health, *A National Approach to Mental Health: From crisis to community: Final Report*, April 2006

Shared Web Services, *5 costly mistakes that cause work flow implementations to fail,* FlowConnect, undated

Social Policy Research Centre, University of NSW, *Stage 1 Evaluation Report: Housing and Accommodation Support Initiative,* NSW 2007

Statistical Information Management Committee (SIMC) www.aihw.gov.au/committee/simc

Ticher, P., Maison, A., Jones, M., *Leading the way to information and communication technology (ICT) success: The report of a study of the issues affecting the use of ICT in the voluntary and community sectors,* Executive Summary, United Kingdom, March 2002

TRI Community Exchange, *IT Support Subscription Terms and Conditions,* undated

UK National Audit Office, *Building the capacity of the third sector,* United Kingdom, 6 February 2009

UNICEF Innocenti Research Centre, *The childcare transition: A League table of early childhood education and care in economically advance countries*, Innocenti Report Card 8, 2008, United National Children's Fund, Italy, p31

US National Council on Disability, *Consumer directed healthcare: How well does it work? 26 October 2004,* United States of America

Wernstrom, E., Weisel, F., *The Camberwell Assessment of Need as an outcome measure in routine mental health care,* Society of Psychiatric Epidemiol, 2006. Vol. 41

Whatcom Council of Nonprofits, *Best Practice in Information Technology Management*, Online 18/11/09, www.wcnwebsite.org

Wood, C., Pennebaker, Dr D., *Non-government sector mental health data dictionary and standard data se,* Health Information Management Association of Australia, undated

Wood, C., Pennebaker, Dr D., *The Non-Government Mental Health Services Information Project Report,* Centre for Mental Health Services Research Inc., Perth Western Australia, October 2000

Wood, C., Pennebaker, Dr D., *A classification of service types and glossary of terminology for non-government mental health services,* Health Information Management Association of Australia, 2004, Vol. 32. No. 2

Ziglin, A. L., *Confidentiality and the Appropriate Uses of Data*, 1995 http://www.mhsip.org/mhsiptest/documents/confid.htm

Zimmermann, A., *Developing Research Capacity in a Community Based Mental Health Agency: Neami Research Framework*, Neami, presented at MHCC/NADA Conference, Sydney 2009

Implementing the National Minimum Dataset for Mental Health Establishments (NGOE) in NSW Community Managed Organisations: Scoping Study

Project Report 1 – 2018

mhcc
mental health coordinating council

Mental Health Coordinating Council
Building 125, Corner of Church & Glover Streets
Lilyfield NSW 2040
PO Box 668 Rozelle NSW 2039

For further information please contact:
Carmel Tebbutt
Chief Executive Officer
Email: carmel@mhcc.org.au
Tel: 02 9555 8388

Julie Millard
Project Lead / Consultant in Mental Health

The project is a Mental Health Coordinating Council initiative funded by the NSW Ministry of Health.

MHCC acknowledge the Australian Aboriginal and Torres Strait Islander peoples as the first inhabitants of the nation and acknowledge the traditional custodians of the lands where we live, learn and work.

MHCC values the lived experience of people recovering from mental health conditions both past and present.

Table of Contents

Acknowledgements

MHCC acknowledge and thank the NSW Ministry of Health for its support of this study, and thanks the many supporters and contributors from the Ministry including the CMO-ERA Project Management Committee, community-based organisations and peak bodies who have been friends and advisors to this scoping study and the project more broadly.

***Better data will improve understanding of how not-for-profits enhance community wellbeing and facilitate macro-level analysis of policy effectiveness.*[1]**

---

[1] Australian Government Productivity Commission, Contribution of the Not-For-Profit Sector, Research Report, Canberra, January 2010, p LV1

Acronyms

AIHW	Australian Institute of Health and Welfare
CES	Carer Experience of Service questionnaire
CLS	Community Living Supports
CMO	Community managed / non-government organisation [2]
CMO-ERA	Community Managed Organisations Expenditure, Resources and Activity
CMHA	Community Mental Health Australia
EACLS	Enhanced Adult Community Living Supports
HASI	Housing and Accommodation Support Initiative
HSIPR	Health System Information and Performance Reporting Branch, NSW Ministry of Health – now known as System Information and Analytics Branch (SIA)
InforMH	Information for Mental Health
METeOR	Metadata Online Registry
MHAODB	Mental Health Alcohol and Other Drugs Branch Queensland
MHISSC	Mental Health Information Strategy Standing Committee
MH CADC	Mental Health Commission Contract Acquittal Data Collection, Western Australia
MHCC	Mental Health Coordinating Council
MH NGOE NBEDS	Mental Health Non-Government Organisation Establishments National Best Endeavours Data Set
MH NGOE NMD	Mental Health NGO Establishments National Minimum Data Set
NDIS	National Disability Insurance Scheme
NMDS	National minimum data set
NGOE	Non-Government Organisation Establishment
PCLI	Pathways to Community Living Initiative
PHN	Primary Health Network
SIA	System Information and Analytics Branch - formerly known as Health System Information and Performance Reporting (HSIPR)
YES	Your Experience of Service questionnaire
YCLS	Youth Community Living Supports

---

[2] ACSQHC Scoping Study on the Implementation of National Standards in Mental Health Services 2014 pg. 7 'The terms 'community-managed organisation' (CMO) and 'community-managed sector' refer to non-government organisations providing services to people with mental health issues. These terms have been adopted as the preferred terms by representative bodies in the sector.'

Executive Summary

MHCC has a long history of advocating for a clear vision for NSW whereby data collection contributes to the improvement of health outcomes for all individuals who live with mental health conditions, their families and carers.

Public CMO data reporting in NSW does not allow for an adequate overview of current service provision by CMOs, with an absence of a knowledge base about community organisation-delivered mental health programs. Therefore, it is difficult to demonstrate how CMOs are contributing to the overall reform process, or a set of consistent outcome measures or indicators to measure effectiveness of service provision and to drive quality improvements.

Data collection and completion of outcome measures have multiple benefits. They provide the opportunity for people with lived experience to tell their story, to be heard and to provide input into their own recovery journey while giving feedback on the quality of the support and services being provided. Collections can also provide CMOs with the capacity to use data for research projects, exchange data with other CMOs to monitor partnership progress on joint projects, capture incidents and monitor processes.

By conducting the *Implementing the National Minimum Dataset for Mental Health Establishments (NGOE) in NSW Community Managed Organisations: Scoping Study (NGOE Scoping Study)*, MHCC aims to progress the project which will ultimately enable access to demographic and outcomes data for quality improvement, benchmarking and population needs based planning in the CMO sector. This will contribute to reliable and consistent data collection across the state and nationally.

However, it takes time to establish trust and a culture of data sharing, which can only occur if a willingness exists to develop collaborative partnerships and create an environment in which all experience the benefits.

MHCC is excited to be progressing NSW CMO data collection that is consistent and beneficial for people with lived experience of mental health conditions and their families and carers whilst supporting the reduction of data or cost burdens.

Stage 2 of the CMO NGOE project aims to determine the best practice approach to implementation of collection of the Mental Health Non-Government Organisation Establishments National Best Endeavours (NGOE) Dataset in scope with NSW CMOs.

Recommendations

1. The national minimum data set be included in all contracts with departments, state and national programs that fund CMOs to provide support and other services – data that is collected once and used often. Appropriate support and training be provided to CMO's to ensure smooth implementation
2. Implementation of the NGOE nationally for all CMOs funded to provide mental health services thereby increasing analysis, and supporting opportunities for service providers and other stakeholders to share information
3. Support consistent use of a range of validated and reliable outcome measures that are collected and considered, with greater value achieved with a broader focus on outcomes rather than only outputs and activities
4. The integration of, and access to, different types of data to be used by a range of stakeholders, including CMO peak bodies in NSW
5. Offer enhanced data reporting that can be used at a CMO, regional and national level to assist with monitoring service delivery to individuals, inform service planning and benchmarking activity[3] and enhance quality improvement initiatives
6. Enable a broader view of comparative data across LHDs and CMOs both at a regional and state level
7. Consideration of the inclusion of other reporting requirements where relevant to CMOs for example outcomes assessments and opportunities for service improvement.

---

[3] This is in line with the current benchmarking that occurs in NSW with Local Health Districts in relation to Adult Non Acute Inpatients, Adult Services and Child and Adolescent Acute Inpatient and Ambulatory Services with regular forums held to discuss data and improve decisions of care.

1. Purpose of the NSW NGOE Scoping Study Project

The NSW Government has committed to system reforms in response to the NSW Mental Health Commission's *Living Well* report [4], including expansion of community-based and CMO services, and a greater focus on ensuring people living with mental health conditions, their families and carers have positive experiences of service delivery, and a commitment to transparency and accountability for all government funded mental health services.

The primary responsibility of the MHCC NSW NGOE Scoping Study Project is to scope the feasibility of implementing the National Minimum Dataset for Mental Health Establishments (NGOE) in NSW CMOs that provide NSW Government funded mental health support services. The Mental Health Coordinating Council (MHCC) engaged a consultant to undertake the scoping study and facilitate consultations with community managed organisations and government agencies.

The Mental Health NGO Establishments National Minimum Data Set, developed in 2014, is a national collection of data on activity, expenditure and staffing for specialised CMO mental health services. There is interest and broad support from NSW CMOs in the implementation of the NGOE. However, scoping is required before implementation can be planned.

The project is an initiative of the Mental Health Coordinating Council, with support from the NSW Ministry of Health.

The Ministry of Health is also considering the lived experience of individuals, families and carers of services, through the introduction of the Your Experience of Service (YES) and Carer Experience of Service (CES) surveys for CMOs.[5]

In scope CMOs for the NGO-E Scoping Study are those providers that are:

- Funded by NSW Ministry of Health, either directly or through contracts with Local Health Districts
- Providing specialised mental health support or care
- Funded and reported within the NSW Mental Health budget.

---

[4] NSW Mental Health Commission 2014, 'Living Well: A Strategic Plan for Mental Health in NSW', Sydney, NSW Mental Health Commission.

[5] Information available at: www.amhocn.org/your-experience-service

Objectives

The objectives of the MHCC project are to provide:

1. Identification of issues to consider when developing processes for data collection, submission, validation and reporting by CMOs
2. Understanding of the background and likely capacity of NSW CMO services to provide annual NGOE data
3. Likely issues in implementing data collection, including clarity of the NGOE data items
4. Consideration of potential alignment of current NSW mental health funded CMOs to the service taxonomy proposed within NGOE
5. Consideration of NGOE implementation in NSW CMOs
6. NGOE implementation approaches being used or planned in other Australian states or territories, or approaches employed in other sectors in NSW e.g. alcohol and other drug (AOD) services
7. Suitability of the current NGOE collection tool developed for use by the Mental Health Commission of Western Australia.

Timeframe

The MHCC project commenced in December 2017 and was finalised in June 2018.

Stages of the NSW CMO–ERA Project

The NSW CMO-ERA Project aims to scope the possible implementation of three nationally developed data collection tools in the NSW CMO sector, and include the data collected in NSW mental health reporting. The data collection tools were developed under the auspices of the National Mental Health Information Strategy Standing Committee (MHISSC) in response to government commitments within the Fourth National Mental Health Plan.

Stages of the NSW CMO-ERA Project included:

- Identification of resources and supports needed for project phase
- Sector consultation on capacity and options for reporting
- Identification of appropriate tools and methods
- Definition of initial scope: service and organisation types in scope for initial reporting

- Development of agreed plan and procedures for data submission, validation and reporting
- Development of plan and requirements for ongoing collection and reporting.

Deliverables

- Project report scoping the feasibility of the implementation of the NGOE in NSW.

Consultation with CMOs

The initial process to consult was a CMO NGOE Consultation Workshop providing an opportunity to garner CMO sector expertise and representation. Consultation with CMOs in NSW who currently receive or may receive NSW Health mental health funds in the future was undertaken through an online survey.

Online Survey

In order to support a wider consultation with CMOs a Survey Monkey questionnaire was developed and distributed to members and non-members of MHCC who currently receive or may receive NSW government mental health funds in the future. The survey was disseminated to CMOs, both members and non-members of MHCC on 24 May 2018, with a deadline of 5 June 2018.

The number of organisations who received the survey is difficult to determine as the survey was distributed widely across NSW. There were 16 surveys completed. It is understood that the end of the financial year is a busy time for CMOs with a number experiencing survey fatigue. Respondents to the survey provided the following information from the questions (specific comments are in italics):

Q. Does your organisation currently receive mental health program funds from the NSW Ministry of Health?

- 43.75% reported currently receiving mental health funds

Q. If the Minimum Data Set is implemented by the Ministry of Health through changes to funding contracts will this be an additional burden for your organisation? If agree, can you provide further information.

- 43.75% agreed the implementation of a MDS would be an additional burden, 37.50% were unclear with 18.75% disagreeing.

- Comments provided were as follows:
    - *Most of this information is already reported to NSW Ministry of Health. The concern is that the effort required to prepare and supply this data may be duplicated subject to the technology used and the format required*.
    - *The Minimum Data Set has no relevance to the central person and no data is being collected of their satisfaction with the service. NDIS was intended to bring in the element of choice, but nothing different to the old system is being implemented. Where is the consumer voice?*
    - *We already have 4 data sets to maintain in the organization. Each one is so specific to the funded program that no one data set captures what the organization does as a whole, therefore we have developed yet another in house data base to do this that makes 5 databases in use.*
    - *It should not be an additional burden if the current MDS we are negotiating for the program is the same.*
    - *It will only be an additional burden if the current Client Information System we use does not already have capacity to capture the required MDS components. Where the information system does not contain components then the CMO is likely to be required to pay for an upgrade to the information system.*
    - *Of course changes to any of the technical requirements will require tech involvement ... and to introduce new variables.*
    - *Training staff to collect data; setting up data collection system; not paid to collect this data.*
    - *As of July 2019 our service will be wholly funded by NDIS. This means PIR … will close... Unfortunately there are few services on the central coast who are funded independently to meet the needs of this group. Many of these [people] will go back through the hospital system and lost the progress they have made with the support of programs like PIR.*

Q. Do you see value in collecting the Minimum Data Set for your organisation?

- 68.75% agreed (12.50% disagreed) there was value in collecting a MDS for their organisation

Q. Do you see value in collecting the Minimum Data Set for the mental health CMO sector in NSW? If you agree can you provide more information on why you see value in collecting the Minimum Data Set and how would you use the data in your planning?

- 81.25% agreed there was value for the mental health sector
- Reasons for data collection were reported as:
    - *Such data is vital for understanding trends and the status of need across the sector, to provide better outcomes for people with a lived experience of mental ill health.*
    - *Means consistency across sector in considering outcomes. Would be useful in establishing parameters around service delivery and projects, collecting data upfront for analysis and reporting re outcomes for comparison between services.*
    - *Standardised MDS would improve integrity of reporting across CMO sector.*
    - *Focus on outcomes not outputs – are we making a difference.*
    - *Data is a key feedback tool (via single and double loop learning)* [6] *in the iterative planning process and allows us to spend more time on the things that make a difference, and less time on the things that don't.*
    - *We currently collect similar data to the MDS and use this to monitor changes in client demographics and respond to these changes.*
    - *MDS collects data on who is accessing services, on what days and for how long. Which is a great way for collecting information for future funding.*
    - *I think the data is already widely available and could easily be aggregated.*
    - *This would allow NSW Health to understand that funded programs are required to support people with mental illness who cannot access NDIS.*

---

[6] Explanation available: https://www.afs.org/blog/icl/wp-content/uploads/2012/11/loop-learning1.png

Q. Will the provision of online support and training for data collection reduce your data burden?

- Only 43.75% agreed that online support and training would reduce data burden. However 31.25% disagreed, with 25% of respondents unclear.

Q. Will it be difficult for your organisation to identify itself to one specific service type? (Please see page 22 for the complete list of CMO service types)

- In relation to the allocation of an organisation to a specific service type 56.25% reported it would be difficult, with 12.50% being unclear in identifying itself to one service type.

Q. What timeframe do you think is required to roll-out the National Minimum Data Set?

- 50% of respondents reported that 6 months would be required to implement the national minimum data set with 43.75% of respondents reporting one year would be required.

Q. What resources would your organisation require to implement the Minimum Data Set?

- Organisations identified a number of resources that would be required to implement the MDS. The following are some of the responses reported:
    - *Training for staff in ensuring accurate collection of data. At a sector level training for executive and senior leaders on how to incorporate insights gathered through data collection into projects that improvements [sic] in capacity, asset utilisation and client outcomes.*
    - *Resources to train and supervise and support staff to collect and record data*
    - *This really depends on how different the National Minimum Data Set is from what is currently being collected. Funding for technical developments and to free up staff to complete training either online or face to face.*
    - *Database enhancement, increased resourcing and relevant training*
    - *Advice on connection with existing IT, training for staff*

  - *A NSW based data entry person. (Potentially) A new data collection system*

  - *Funding for technical developments*

  - *Needs consumer orientation with additional questions.*

  - *A case [sic] management software package. We have been wanting to introduce but don't have the funds available for a specific program.*

Q. How would you rate your organisation's capacity to provide a quarterly Minimum Data Set and report to the Ministry of Health?

- 37.5% of respondents rated their capacity to provide a quarterly MDS and report to the Ministry of Health as above average, 50% reported as average, with 6.25% as below average.

- A number of CMOs provided additional information as to their rating, reported as follows:

  - *We currently provide a variety of MDS data based on the requirements of particular contracts this would be no different once we are given a clear specification and time and resources to implement it.*

  - *NDIS has drawn a lot of resources from the organisation and left little infrastructure to support implementation of new processes.*

  - *Must be consumer oriented otherwise it is just irrelevant to their needs and more of the same.*

  - *Many volunteers involved in delivering supports and this would require a lot of training for a large non paid workforce.*

It is evident from the survey responses that CMOs are welcoming of the need for consistent data collection and a minimum data set, although CMOs have reservations about the impact on employee time, cost burden and systems upgrades of an additional data collection set.

2. Changed Community Managed Sector Landscape

Over the past decade the landscape in NSW has substantially changed for the community managed mental health sector. This has occurred as a consequence of mental health reform at both a State and Commonwealth level and more recently due to the roll-out of the NDIS. This reform includes but is not limited to the following points:

- A focus on the lived experience, choice and control, person centred care and improving physical health
- The imperative for trauma informed recovery oriented practice, programs and suicide prevention services
- Growth of a peer workforce
- Reform, innovation and collaboration between and within sectors
- Establishment of the National Mental Health Commission and the Mental Health Commission of NSW in 2012
- Relevant reports, legislation and frameworks:
    - A National Framework for Recovery-Oriented Mental Health Services 2013
    - Fifth Mental Health and Suicide Prevention Plan, and Implementation Plan 2017
    - Living Well: A Strategic Plan for Mental Health in NSW 2014
    - National Review of Mental Health Programmes and Services Report 2015
    - National Mental Health Commission, A Contributing Life: the 2012, 2013, 2014 and 2016 National Reports on Mental Health and Suicide Prevention
    - National Mental Health Commission 2017 National Report on Mental Health and Suicide Prevention
    - NSW Mental Health & Forensic Act amendments 1997 – 2018
    - NSW Mental Health Reform 2014-2024
    - NSW Ministry of Health GIMP (Grants Management Improvement Program) that evolved over 6 years into the MHB Partnerships for Health

    (P4H) community sector reform process and resultant agreed contracted key performance indicators[7]
  - NSW State Health Plan: Towards 2021

- Focus on competitive tendering and its impacts with the aim of achieving a robust efficient and dynamic sector. However, these processes can disrupt and negatively impact on service users and support workers, local community partnerships, and established organisational infrastructure resulting from tender decision[8]
- Community based care with resultant programs CLS, PCLI, and service hubs such as LikeMind
- National Disability Insurance Scheme pilot sites in 2013 and full roll-out commencing in 2017
- Fewer contractual arrangements and an 'apparent inherent bias toward larger providers at the expense of local knowledge and expertise that smaller providers have developed'[9] resulting in the need for the amalgamation of smaller and often specialised CMOs
- Establishment of Primary Health Networks in 2015, previously Medicare Locals
- 'Commonwealth pooled funding of mental health programs to Primary Health Networks (PHNs)'[10] and resultant commissioning of mental health services and regional stepped care approach to mental health and suicide prevention
- Greater involvement of large faith based organisations in providing mental health funded services
- NSW Ageing, Disability and Home Care services transitioning to Department of Family and Community Services (FACS)
- The development and introduction in 2018/2019 of the YES and CES surveys and Guides[11] for CMO use[12].

---

[7] Strengthening Mental Health Care in NSW (undated) www.health.nsw.gov.au/mentalhealth/reform/Publications/mental-health-care.pdf

[8] MHCC View from the Peak Oct 2017 p5

[9] MHCC View from the Peak Oct 2015 p3

[10] One year on: Progress Report on the implementation of Living Well: A Strategic Plan for Mental Health in NSW 2014-2024 cited MHCC View from the Peak Feb 2016 p2

[11] Available at: www.aihw.gov.au/reports/mental-health-services/mental-health-services-in-australia/national-mental-health-committees/mental-health-information-strategy-standing-committee/your-experience-of-service-survey-instrument

[12] It is understood that a YES survey is currently being developed by the Australian Mental Health Outcomes and Classification Network (AMHOCN) for use by Primary Health Networks.

3. Current Mental Health Funded Programs in NSW

The NSW Ministry of Health funds a range of community mental health programs for which the implementation of the NGOE may be relevant. These range from mental health promotion, to, helplines, to face to face counselling and supports, to residential services.

"The value of our services is realised through an understanding of how our services improve the quality of life for our clients.
Data is at the core of understanding the correlation between our activities and the outcomes achieved for clients."

Respondent MHCC *National Minimum Data Set CMO Consultation* Survey May 2018

4. CMO Data Collection: A History

MHCC has a long advocated for a coordinated approach to data collection, including supporting and enhancing CMOs' ability to produce comprehensive data that reports activity and meaningful outcome data while not substantially increasing the reporting burden. This is evidenced by the projects and work undertaken by MHCC over the past 14 years, as follows:

2004 – 2007 - NSW NGO Development Strategy: Mental Health

MHCC worked to build the profile and capacity of NGOs providing mental health rehabilitation and recovery services in NSW. The Strategy concentrated on three main areas of activity: Workforce development; Outcomes and quality; and Promoting partnership.[13] During 2006-2007 MHCC worked to develop a sector wide approach to the collection, distribution and use of data about service activity.

2007 – Routine Consumer Outcome Monitoring Project

The Routine Outcome Monitoring Project conducted by MHCC involved preparing the non-government mental health sector in the use of consumer outcome measures to improve service planning and delivery. The project was informed by the needs of NGOs identified in the NSW NGO Development Strategy: Mental Health Report. Workshops on outcomes and their use with NGOs were facilitated by MHCC across NSW.

2010 – NSW Community Managed Mental Health Sector Mapping Project

MHCC completed an extensive mapping of the NSW community managed mental health sector from 2008 to 2010. This involved a detailed survey of CMOs, a capacity-building literature review and multiple stakeholder consultations. The information was further updated in 2013 as part of the MHCC Sector Benchmarking Project. The report was designed around a framework for building sector capacity comprising four sector capacity elements of: client experience; service provision; research and development; policy and planning.

2010 - NSW Community Managed Mental Health Sector Data Management Strategy Phase 1

From February 2009 to May 2010 Mental Health Coordinating Council undertook the Data Management Strategy Project, Phase 1 with funding from NSW Health. The

---

[13] www.mhcc.org.au/media/13206/final-report-ngo-development-strategy11-2008.pdf

project sought to explore how CMOs working in mental health in NSW could apply technology to make optimal use of the information gained through program delivery thereby improving outcomes for individuals. The development of an evidence-based, recovery-oriented CMO service system that enhances knowledge creation and management, improves relationship outcomes for individuals and carers, reduces administrative burden for CMOs and builds on quality performance systems was the focus of the Strategy.

The major achievements of the project were extensive consultation with CMOs, over a year through three working groups and forums, with the development of data sets, both comprehensive and minimum for application by the broad mental health community managed sector. The data sets developed were consumer-focused, recognised the role of families and carers, had rationales for inclusion of data elements and were compatible with the national data dictionaries. In addition, the project established a set of criteria against which organisations could assess the applicability of data systems to their specific requirements including links to human resource and work health and safety processes.

2011 - Mental Health Non-Government Organisation National Minimum Data Set Project

The Mental Health Non-Government National Minimum Data Set Project represented a significant step toward establishing a national mental health NGO data collection. Community Mental Health Australia (CMHA)[14] through MHCC and in partnership with the Australian Institute of Health and Welfare (AIHW) worked on the project from March till July 2011. The Mental Health NGO NMDS project aimed to develop a mental health non-government organisation national minimum data set.

The main purpose for collecting nationally consistent information on the activity of mental health NGOs was to provide reliable data to better inform policy, practice and planning of national mental health NGO activities to support Australians living with mental health conditions, their families and carers. The project was undertaken through a process of consultation with Australian state and territory government funders, mental health CMO peak bodies and CMOs. A national consultation workshop was held on 8 June 2011.

---

[14] CMHA is the alliance of state and territory mental health peak bodies.

The project deliverables included a mental health NGO service taxonomy, a data set specification for the national collection and a preferred data collection methodology, with a report of the project completed.

2011 - Data Management Strategy Business Plan and Funding Proposal – Phase Two

This second phase of the Data Management strategy for MHCC included a scoping study to determine the technology infrastructure requirements of CMOs working in mental health in NSW, and the development of a business plan to enhance CMOs' technology capacity. The business plan involved significant investment in resources that were beyond the scope of the project.

2013 - 2014 – Development of Mental Health NGO Establishments National Minimum Data Set

MHCC represented CMHA on the working groups developing the Mental Health NGO Establishments National Minimum Data Set (MH NGOE NMDS) which was planned to be implemented in 2014-2015. This work was undertaken by AIHW for the Mental Health Information Strategy Standing Committee (MHISSC).

The primary purpose for the creation of the NGOE NMDS was to collect nationally consistent information on the activity of CMOs working in mental health, and to provide reliable data to better inform policy, practice and planning of national mental health NGO activities.

The scope of the MH NGOE NMDS is that any mental health-related CMO funded to provide services under one or more of the service types should be included in the service type taxonomy. This taxonomy is also becoming the basis of other national and state service mapping and planning projects. The collection methodology for the MH NGOE NMDS requires a CMO to provide aggregated data to its respective funders, at either state and territory or national levels. The funder is then responsible for submission to the AIHW. Depending on the funder this information may be required to be collected through the AIHW's own collection tool.

CMO mental health service types are:

1. Care coordination
2. Counselling - face-to-face
3. Counselling, support, information and referral - online
4. Counselling, support, information and referral - telephone
5. Education, employment and training

6. Family and carer support
7. Group support activities
8. Individual advocacy
9. Mental health promotion
10. Mental illness prevention
11. Mutual support and self-help
12. Personalised support - linked to housing
13. Personalised support - other
14. Sector development and representation
15. Self-help—online
16. Service integration infrastructure
17. Staffed residential services

The *Mental Health Non-Government Organisation Establishments National Best Endeavours Dataset* (NGO-E) is an annual collection of aggregate data on service funding, staffing and activity i.e. clients and contacts. It was developed in consultation with the CMO sector.

The NGO-E has been implemented in several states and remains the current national standard for reporting.'

2013 - 2015 – National Community Managed Organisation Outcome Measurement Project

MHCC funded by the Department of Health and Ageing (working on behalf of CMHA) reviewed the use of outcome measures in mental health related community managed organisations (CMOs) across Australia. This was in partnership with the Australian Mental Health Outcomes and Classification Network (AMHOCN).

The final report[15] outlines recommendations on measures that have the most potential for use in Australia across the various mental health CMO service types, and identifies information infrastructure development issues that would need to be considered to introduce reporting of consumer outcomes. The resulting Guidebook[16] published in 2015 details the measures most appropriate for the different domains of

---

[15] Australian Mental Health Outcomes and Classification Network (AMHOCN) and Community Mental Health Australia, 2013, National Community Managed Organisations (CMO) Outcome Measurement Project Report
[16] AMHOCN and Community Mental Health Australia, 2015, Implementing Routine Outcome Measurement in Community Managed Organisations

community mental health sector, as well as focus and activity. It also provides advice on how to introduce the collection of routine outcome measurement. It explores their uses and application in community organisations, the importance of consumer and carer participation, workforce training and education and outlines the benefits, including consumer outcomes, service improvement, service comparability and value for money.

2016 - Proposal for a Community Managed Mental Health Sector Development Plan/Strategy

In February 2016, Mental Health Coordinating Council (MHCC) provided a Briefing Note to both the Mental Health Commission of NSW and the NSW Minister of Health presenting an argument to fund support for a Community Managed Mental Health Sector Development Strategy. MHCC Members were provided with this information at a Members Forum.[17] One of the members' priorities identified at that forum was a CMO Data Management Strategy. The briefing note referred to the NSW CMO Data Management Strategy (2010) and its achievement of sector consensus on a Minimum Data Set and the production of a business plan for data system capability for NSW Health funded mental health CMOs.

The briefing note recommended that 'district co-ordinating structures have access to timely, local and comparative data on the mental health and wellbeing of their populations, including in housing, health, justice and welfare. Districts should set up arrangements for the appropriate sharing of individual-level data for shared clients who have high rates of service access.

The proposal for a CMO Data Management Strategy included:

- Implementing national CMO data set specifications
- Implementing YES survey for CMOs
- Benchmarking consumer outcomes
- Supporting IT system upgrades

Also recommended was the need:

- To ensure that data informs planning and review cycles and that reports are

---

[17] Mental Health Coordinating Council Member Consultation – Sector Development Plan/Strategy Briefing Note May 2016

provided regularly to the community about its mental health and wellbeing through the CMO Data Management Strategy (by informing Mental Health Commission of NSW annual reports and Ministry of Health annual reporting).

- For the NSW Ministry of Health to establish a community-managed sector development plan that includes strategies to strengthen and expand the community sector workforce and improve the management and collection of data.

2017 - Bilateral Agreement between the Commonwealth and NSW

The 2017 Bilateral Agreement between the Commonwealth and NSW sets out a suite of reforms (in the priority areas of aged care integration, palliative and end of life care, mental health, multidisciplinary team care, and rural and remote service delivery) to progress the Council of Australian Government's (COAG) commitment to enhanced coordinated care, as articulated in the Addendum to the National Health Reform Agreement (NHRA): Revised Public Hospital Arrangements for 2017-18 to 2019-20 (the NHRA Addendum).

The overarching objective of the Agreement is to support the implementation of coordinated care reforms, consistent with the principles outlined in the NHRA Addendum that improve patient health outcomes; and reduce avoidable demand for health services.

The Agreement clearly identifies as a Key Milestone the need to: identify feasibility of future data collection, analysis and linkage between health and social services data, considering: NSW-held datasets including mental health data, and NSW family and community services data (child protection, social impact investment).[18]

2018 – Key Projects Mental Health Commission of NSW

The Mental Health Commission of NSW is an independent statutory agency responsible for monitoring, reviewing and improving mental health and wellbeing for people in NSW. The Commission is currently undertaking two projects in NSW: the *Building Community-Based Mental Health Services and Supports Project* and the *Review of Headline Indicators to Monitor Mental Health Reform Project*.

---

[18] Bilateral Agreement between the Commonwealth and New South Wales: Coordinated care reforms to improve patient health outcomes and reduce avoidable demand for health services, 2017 page 15 www.federalfinancialrelations.gov.au/content/npa/health/other/Signed_bilateral_agreement_NSW.pdf

1. Building Community-Based Mental Health Services and Supports Project [19]

In 2017, the Commission undertook a preliminary scoping exercise which identified a number of qualities required by effective systems of community-based services and supports. The Building Community-based Mental Health Services and Supports Project aims to:

- understand and describe the characteristics of an effective network of wholistic and comprehensive community-based mental health services and supports,

- use that understanding to develop a set of evidence-based principles and recommendations to guide their planning, delivery and monitoring, and
- achieve consensus on, and commitment to, use of the Principles to plan, develop and monitor a system of community-based mental health services and supports in conjunction with people who experience mental illness, their families and carers.

The project is being conducted in two-phases. Phase One (the current focus of work) includes describing and examining a range of best practice case studies and a selection of case study site visits (in metropolitan, regional and rural localities) to understand how programmes work, from the perspective of stakeholders and interest groups. Phase One also includes a large-scale stakeholder survey which will enhance the consultative reach of the Project by seeking relevant perspectives on the characteristics, enablers, barriers, and desired outcomes of a well-designed service and support system

Phase Two of the project will involve the development of a set of draft best practice principles and workshops with senior representatives of stakeholder groups (across NSW) to test the principles and their implications for the sector. The final Project Report will be used by the sector to plan, develop and monitor a system of community-based mental health services and supports.

2. Review of Headline Indicators to Monitor Mental Health Reform Project [20]

The main objective of the project is to review and develop the current set of ten indicators to ensure sufficient, appropriate and effective system level monitoring of

---

[19] Discussion with Karen Burns Deputy Commissioner MHC of NSW on 7/2/18, and Project Information sheets (undated) received 18/6/18

[20] Review of Headline Indicators to Monitor Mental Health Reform Project Information Sheet (undated) received 18/6/18

progress reform, from whole-of-government and whole-of-life perspective.

As a part of the Commission's system reviews process, this project seeks to conduct a rigorous, timely and fit-for-purpose review of the Commission's existing headline indicators that enables the Commission to effectively monitor current progress of NSW mental health reform in both the system and population outcomes.

2018 – MHCC CMO NGOE Project

MHCC will continue its work with NSW Health in support of enhanced data collection for NSW CMO services. Stage 2 of the joint CMO Expenditure, Resources and Activity (CMO-ERA) project aims to scope the reporting of data on activity and expenditure in the mental health sector and determine the best practice approach to implementation of collection of the Mental Health Non-Government Organisation Establishments National Best Endeavours (NGO-E) Dataset in scope with NSW CMOs. The project will broaden the scope of the NGO-E to assess the feasibility of consolidating the performance monitoring collections, while considering the reduction of data burden on CMOs.

5. Benefits and Issues of NSW CMO Data Collection

Data collection and completion of outcome measures have multiple benefits. They provide the opportunity for people with lived experience to tell their story, to be heard and to provide input into their own recovery journey while giving feedback on the quality of the support and services being provided. Collections can also provide CMOs with the capacity to use data for research projects, exchange data with other CMOs to monitor partnership progress on joint projects, capture incidents and monitor processes.

MHCC's Data Management Strategy Report (2010, p. 44) identified that 'Many CMOs working in mental health in NSW are under significant pressure, due to the diverse reporting requirements of multiple funders.' There are various funders for CMOs, including multiple state and Commonwealth government departments with most requiring mandatory regular reporting on a range of output and performance indicators. CMOs are also recipients of grants administered by aged care and disability services and Primary Health Networks (PHNs). The administrative burden on CMOs to collect data and produce reports is increasingly complex and time-consuming.

There are competing needs between funders, with their focus on accountability, strategic planning, competitive tendering, costs, privacy and outputs, and the CMO sector with its focus on individual improvement, outcomes, capacity building, data sharing, community growth, evaluation, planning and service quality improvement. One of the concerns raised by CMOs articulated in the WA report of 2015-2016 is the lack of provision for the reporting of outcomes or qualitative data.[21]

There are fifteen local health districts covering Sydney metropolitan and rural and regional NSW. In addition, two specialist networks focus on children's and paediatric services, justice health and forensic mental health. A third network operates across the public health services provided by the St Vincent's Hospital Network. There is no centralised information site publicly identifying expenditure of funds on specific mental health services and what the current mental health funded programs are.

See Appendix A, for further information on outcome measures and their benefits. Appendix B contains a summary of Outcome Measures Used in NSW.

It is understood that CMOs commonly provide a diversity of services some of which

---

[21] www.mhc.wa.gov.au/media/1605/ngoe-evalution-report-2015-16.pdf

are not specifically or fully funded. These services would not be considered with allocation to a service type or when reporting against a service type. Examples of this may include but are not limited to: health literacy, resource development and distribution, emergency relief, community outreach, engagement and consultation with people with lived experience, families and carers and the wider community, or research. It is recognised that research and CMOs' capacity to reach a broad cross section of society is currently underutilised in NSW.

In 2014 the Scoping Study on the Implementation of National Standards in Mental Health Services identified (ACSQHC, p. 35) that: '*an industry has been created around the collection of irrelevant data*', and '*that information should be shared so that people are not duplicating work that has already been produced*' (p. 38).

As reported in the *Open government data and why it matters* report: '*Access to open government data in Australia is economically important, as confirmed by multiple theoretical and empirical studies, with varying estimates of its net positive benefit. Some of these benefits include new data-driven products and services, increased operational efficiency in both the public and private sectors, and improved engagement from the public*.'[22]

There is a potential for benchmarking, workforce planning and training, and equitable distribution of resources as a result of collecting NGO-E data. The proposed NGOE implementation would assist with a consistent data collection, however greater value would be achieved if there was a broader focus on outcomes rather than only outputs and activities.

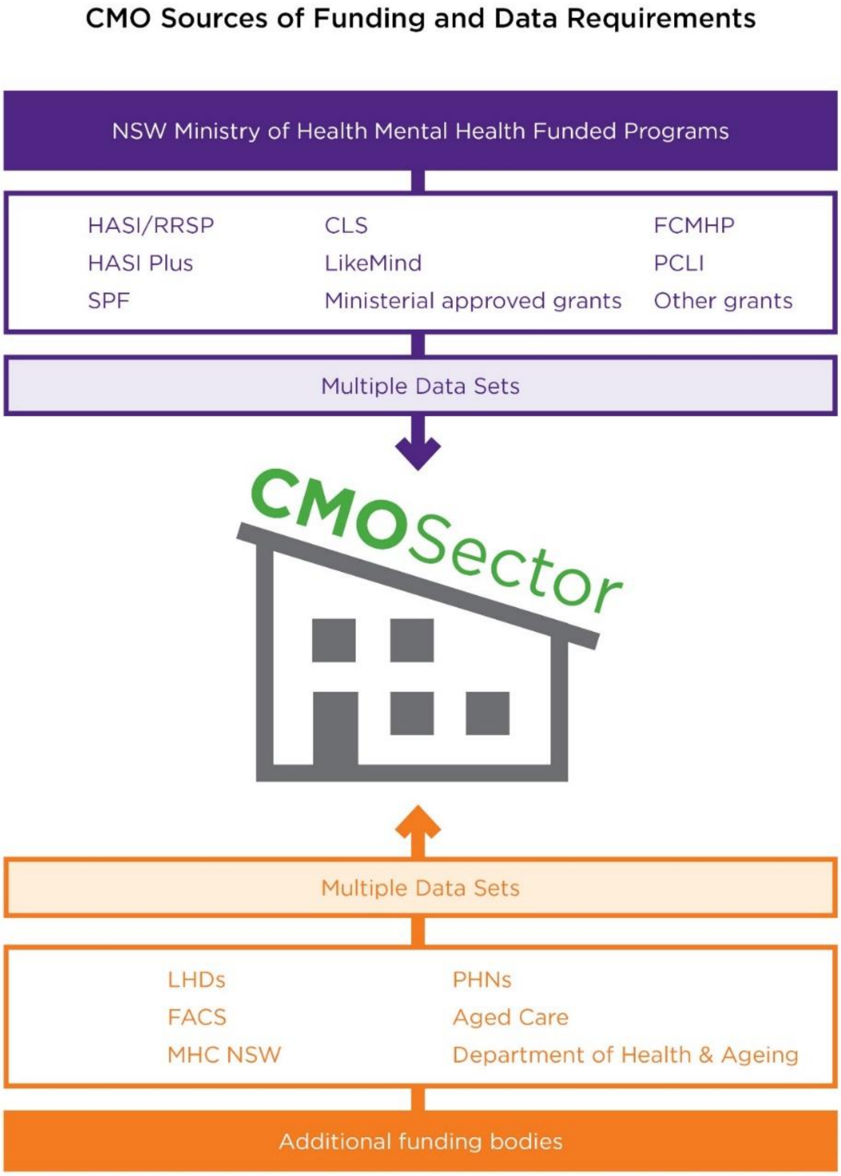
"Consistent data across services is very useful to provide best practice care to service users."

Respondent MHCC *National Minimum Data Set CMO Consultation* Survey May 2018

---

[22] Commonwealth of Australia 2016 Executive Summary (p. 4)

Diagram 1: Existing NSW CMO Sources of Funding and Data Requirements



CMO Sources of Funding and Data Requirements

NSW Ministry of Health Mental Health Funded Programs

HASI/RRSP
HASI Plus
SPF
CLS
LikeMind
Ministerial approved grants
FCMHP
PCLI
Other grants

Multiple Data Sets

Multiple Data Sets

LHDs
FACS
MHC NSW
PHNs
Aged Care
Department of Health & Ageing

Additional funding bodies

6. Taxonomy Use Comparison

The scope of the Mental Health Non-Government Organisation Establishments National Best Endeavours Data Set (MH NGOE NBEDS) is mental health-related non-government organisations that provide one or more of the service types included in the service taxonomy:

Appendix C identifies a comparison of NMDS service taxonomy (17 items), and taxonomy use by Western Australia (13) and Queensland (17).

7. NGO-E in Other States and Territories

To date Western Australia and Queensland have implemented a data collection system for community managed organisations.

Western Australia

The data collection for contract acquittal of CMOs that are funded by the WA Mental Health Commission went live in Western Australia in December 2013. All CMO mental health service providers that receive funding are required to complete the MHC CADC. That is CMOs that provide services under one or more of the service types included in the service taxonomy. There are seven Health Regions in Western Australia, and 14 service types included in the data collection.

The WA data collection system aims to:

- Improve consistency and quality of data
- Consolidate data reporting procedures
- Streamline the reporting process for NGOs
- Meet contract and future national reporting requirements.

An Online Data Collection (MH CADC) Instrument User Guide (with Frequently Asked Questions section) was developed and distributed with improvements over time to enhance reporting consistencies and validation functionality. Mental Health Commission Contracts include information on allocation of service type(s) and contract reporting requirements.

There are two reporting periods – June and December, with reporting deadlines on 25 July and 25 January. The Mental Health Commission procured the services of

WebSurvey[23] as the organisation that developed and hosts the online data collection instrument. Access is by a secure webpage with a secure link emailed to the authority for each mental health service provider.

A Helpdesk is maintained by the Mental Health Commission. Error messages occur when: Data is entered in the incorrect format; Data is entered outside applicable ranges; Mandatory data fields have not been completed. A Validation Summary is included in the Print View of the report which provides some calculated fields for example, cost per service hour, proportion of staff hours in service delivery etc. to assist organisations with assessing their data prior to submission.

Other reporting requirements consolidated in the State Data Collection (SDC) of 2014/15 include, where relevant to CMOs the following: Annual standards and outcomes assessment; Carers Recognition Act; Disability access and inclusion plan; financial reporting; and opportunities for service improvement.

The primary purpose was to standardise data (with the recognition that only establishment data is being collected) and to reduce the burden on CMOs by using a web-based system for data entry. It was reported that: 'no one system meets everyone's needs particularly in relation to client management data'.[24]

The third evaluation in February 2016 via Survey Monkey provided feedback from 51 (of 76) CMOs. The resultant report[25] for Western Australia identified 86% satisfaction with the reporting system, with 76% of respondents reporting a reduced administrative reporting burden. 86% of respondents found the historical data useful, 76% the Help Desk, with only 54% finding the training useful. It is noted that a number of respondents reported becoming familiar with data entry and therefore not requiring additional training. Technical issues identified related to saving or printing data.

In December 2016, the NGO-E SDC system rolled out an additional process to allow the MHC Contract Managers direct access to data submitted by the organisation. This new review process allows the Contract Managers at the Commission and the CMO to resolve any data issues directly within the system (cited p. 26).

---

[23] WebSurvey is an online survey, hosted in Melbourne and priced using a per-use model. Online survey set up costs begin at $2200 +GST and a usage fee of $1.50 +GST applies per respondent. Information from website on 6/3/18 www.websurvey.com.au/

[24] Telephone discussion with Trevor Dare of WA Mental Health Commission on 6/2/18

[25] Government of Western Australia, The Evaluation of the Mental Health Non-Government Organisation Establishment Reporting System 2015-2016

Data transfer from the NGOs to the MHC is performed through report submission using the MH NGOE SDC web-based reporting instrument. Data which is applicable to the NGOE NBEDS is forwarded to the AIHW annually by the MHC.

The Contract Manager at the MHC may identify an issue with the data collection. The CMO is notified and will address the identified issue(s) by either correcting the data (if inaccurate) or providing clarification or further information via a comment.[26]

Overview of Reporting Process in WA is shown as:

Queensland

The Mental Health Alcohol and Other Drugs Branch (MHAODB) Queensland contacted all non-government organisations funded by the Department of Health inviting them to participate in a pilot quarterly data collection for a new online reporting mechanism. Fifteen, of thirty-five, organisations who provide mental health services participated in the pilot for the data set and provided feedback to the MHAODB about the process.

Contracts were changed across the state and the Mental Health Non-Government Organisation Establishment Data Set was made mandatory for all mental health funded organisations in Queensland from the reporting period of 2016-2017. MHAODB procured the services of WebSurvey. As the contract acquittals are quarterly so is the data collection, although the data accumulates. There are 17 service types involved in the data collection. Please see Appendix C for service taxonomy use comparison.

The Clinical Systems Collections and Performance Unit of MHAODB provides ongoing CMO support, a helpdesk and quarterly reports. The first year of data collection is

---

[26] Western Australia Mental Health NGOE SDC Online Data Collection Instrument User Guide, 2017/18 pg. 29

under review, with ongoing changes occurring to the online tool, user guide and data guide specifications.[27]

Issues that are being identified in the first year of data collection include but are not limited to the following:

- Data collection is quarterly, in line with contract acquittals. There is consideration to making the collection to six-monthly to decrease CMO burden and support improvements to the tool
- The first year of data has data quality issues with an ongoing need to advise in relation to definitions, with a 'best effort' entry if unclear where data is entered
- The ability to resubmit data is limited though this can be corrected in the next quarter
- High-level turnover of staff in CMOs resulting in the need to manage increased access and support for new users
- Location of service is linked to Hospital and Health Services (similar to NSW Local Health Districts) of which there are 16 in Queensland, and not specific to a town or city
- Some measures do not accurately describe what services are provided with CMOs wanting to include qualitative and outcome data
- The status of the Quality Accreditation/Certification Standard Indicator and Outcome Measurement Tool Indicator were changed to an annual question, in the 4th quarter, as they were repetitive
- A data report is provided to CMOs, however as yet, there are no sector reports for Queensland.

Each CMO nominates an Organisation Authority that is responsible for ensuring the organisation's capture, recording, storage and reporting of data. Data cleaning is reported as initially challenging with the need for logical validation and consistency of data entry over time.

If data is not submitted or incomplete, in the final week of the reporting month, CMOs are followed up via telephone by the Systems Collection Team of Queensland Government. One month following the data collection period deadline the process is handed over to the Community Services Funding Branch of the Queensland

---

[27] Telephone discussion with Garry Thorne and Lee Roberts from Clinical Systems, Collections and Performance Unit MHAODB Queensland on 9/1/18

Government to progress their contract compliance processes with the outstanding organisations.

CMO Peak Bodies of Western Australia and Queensland

The peak bodies of WA and Queensland were contacted to discuss involvement with implementation of the NGOE. Feedback provided included:

- Initial consultation about the process but no further development of the system (QLD)
- Peak body not involved in data cleaning or CMO contact
- Specific data on the sector is not provided to the peak body although this has not yet been requested as less than one year of implementation (QLD)[28]
- There were no major issues identified by the sector with implementation, due to the high level of ongoing training and access to telephone support.

8. Other Data Collections

NSW Drug and Alcohol Services

The Alcohol and Other Drug Treatment Services National Minimum Data Set (AODTS NMDS) overseen by the Commonwealth Department of Health is the national collection of a defined set of treatment data elements agreed upon by all states and territories. The NMDS is a subset of the agreed NSW Minimum Data Set for Drug and Alcohol Treatment Services (NSW MDS DATS) which has a number of additional items.

NADAbase is an online client treatment and outcomes database built and supported by NADA for its membership. NADA, as the Network of Alcohol and other Drugs Agencies is the peak organisation for the non-government drug and alcohol sector in NSW. NADA represents over 100 organisational members that provide a broad range of services including alcohol and other drugs health promotion, early intervention, treatment, and after-care programs. These community based organisations operate throughout NSW. They comprise both large and small services that are diverse in their structure, philosophy and approach to alcohol and other drugs service delivery.

---

[28] The Consultant was advised that a statewide report is being developed, with Queensland service level data to be presented at a CMO Contract Forum in March 2018

NADAbase is the combined NADA provided database for National and NSW Minimum Data Sets for Alcohol and Other Drug Treatment Services (N/MDS) and Client Outcomes Measurement System (COMS). It provides a comprehensive system of client data collection and reporting free to NADA members. Support and online tutorials[29] and data cleaning are provided by NADA. The tutorials are designed to assist organisations in navigating NADAbase and to effectively input, extract and report on the client data collected.

The National Minimum Data Set (NMDS) and the NSW Minimum Data Set (MDS) for Alcohol and Other Drug Treatment Services (AODTS) consists of a range of items describing administrative, social, demographic, drug-related and service-related information. The data set was developed in conjunction with service providers to ensure data elements are useful to individual organisations needing consistent, accurately defined information for service development and planning and at a Commonwealth or state level. The unit of measurement for the N/MDS is a Service Episode. For a list of Data Collection Items please see Appendix D.

An NSW MDS Data Dictionary 2015,[30] and a set of requirements and guidelines for completing of the NMDS and NSW MDS and for collecting information on Indigenous status are available.

NADA has maintained some of the items in NADAbase that have been removed from the NSW MDS in relation to Service Delivery Setting (Outreach Setting) and Main Service Provided (Day Rehabilitation Activities) and mapped according to NSW Government guidelines for the data extract.

On 1st July 2017, three new data collection screens were made available to NADAbase users that have the potential to not only enhance client care but to also increase the evidence base of clients experiencing these issues. The screeners are attached to each client episode and form part of the initial assessment to inform care planning around issues related to suicide risk, domestic and family violence and blood borne virus and sexual health.

The goal of the Client Outcomes Measures System (COMS) development was to improve the way outcomes of care are measured in non-government alcohol and

---

[29] http://tutorial.nada.org.au/

[30] Available at: http://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2015_014.pdf

other drugs organisations in NSW, with a particular focus on co-occurring disorders and mental health outcomes in alcohol and other drugs services.

In December 2009, after extensive consultation with the Advisory Committee and after seeking other expert advice: after thorough consideration of the Review of Measures report and other published reports and in light of the findings from the Baseline Evaluation in 2009, NADA released its Outcomes data set and the document: *Determining the Treatment Outcomes Dataset* (2009).[31]

New Zealand Programme for Integration of Mental Health Data (PRIMHD)

The Programme for Integration of Mental Health Data (PRIMHD) includes non-government organisations who work in the mental health and addiction[32] sector.[33] PRIMHD was developed by the Ministry of Health in New Zealand to combine a legacy Mental Health Information National Collection with a separate collection of local District Health Board (DHB) outcome data. The intent is to provide a single rich data source of national mental health and addiction information that can be used for multiple purposes by a range of different stakeholders including the Ministry, DHBs and NGOs.

DHBs and NGOs that provide publicly funded mental health and addiction services send data identifying their service user referrals, activities and any outcomes (e.g. HoNOS - DHB only) to the PRIMHD database at the Ministry using secure electronic information transfer protocols.

PRIMHD can be used to produce a range of reports for the Ministry and the wider mental health sector. NGO service data can be shared with similar services for benchmarking service delivery practices and considering the effects of different models of care.

---

[31] Sighted on NADA website on 7/2/18

[32] Terminology used in New Zealand

[33] Platform Trust, NGO Guide to PRIMHD, July 2016 www.platform.org.nz/OurPublications

9. NGOE Implementation in NSW

A successful CMO NGOE implementation in NSW requires commitment from government and CMOs and an integrated service delivery model.

The NSW CMO response to the implementation of the NGOE is considered to be favorable due to longevity and involvement in the pursuit of a minimum data set. As reported in the MHCC Annual Report[34] in 2017: *For many CMOs the greater attention to agreed contracted KPIs is welcomed and will hopefully, as anticipated, provide stronger engagement with LHDs around activity and outcomes*.

CMOs understand the need for data and its benefits. However the ultimate data goal for CMOs is to '*collect once and use often*'.

In 2011 when the MHCC Data Management Systems Business Plan was developed it was determined that a 'one solution for all' approach was not possible due to the technical and practical limits. However, portal-based technologies now permit centralised data collection with only a need for Internet access.

What will be required for implementation?

- A clear vision for NSW whereby data collection contributes to the improvement of health outcomes for all individuals who live with mental health conditions, their families and carers
- The determination of costs for set-up and implementation of CMO NGOE in NSW
- Stage 2 of the project to determine and support implementation of the NGOE for CMOs funded to provide mental health services
- Communication strategy that regularly consults with and informs the CMO sector about a proposed implementation of NGOE data collection
- Clear and concise information to CMOs about the roll-out, timeframe for implementation and expectations of data collection completion
- Access to a reliable and secure web portal for data collection and reporting
- Development (or modification) of a Data Dictionary and User Guide for NSW in relation to mental health funded services is required before implementation

---

[34] MHCC Annual Report in 2017 page 4

- Realistic data collection periods[35] as determined in contract acquittals with data being accumulative.
- Reduction of data burden for CMOs. As reported in the WA Evaluation Report[36]: '…it is also evident that the needs for additional information need to be balanced against the level of reporting burden placed on organisations.'
- Data collection by programs as documented in contracts is in line with the NMDS to avoid duplication
- Recognition of the diversity of service delivery models within a service type.
- Clear and articulated definition of service types. For example, the WA Data Collection 3.1 states: 'It is the Mental Health Commission's responsibility to allocate the services they fund to a service type. Services will be allocated to a service type based on the principal function they are funded to provide. If an NGO is funded to provide one type of service, it can only be allocated to one service type. However, if an NGO is specifically funded to provide more than one type of service, the activity for each type of service should be collected under each relevant service type'[37]
- Consultation and negotiation with CMOs for all new contracts, variation to contracts or contract renewal in the allocation of CMO programs to service types
- Ongoing education, training and the nurturing of a culture of support via a Helpdesk for CMOs through MHCC, or InforMH at the Ministry of Health
- Provision of regular reports to CMOs and to the NSW CMO sector through the peak body

---

[35] It is noted that Queensland is considering six monthly data reporting. See section: NGOE in Other States and Territories in this report

[36] Government of WA Mental Health Commission, Evaluation of the NGOE Reporting System 2015-16 pg. 18

[37] As seen in the WA Mental Health NGOE In-Brief 2014/15: page 24 – Service Types

Recommendations f

1. The national minimum data set be included in all contracts with departments, state and national programs that fund CMOs to provide support and other services – data that is collected once and used often. Appropriate support and training be provided to CMO's to ensure smooth implementation
2. Implementation of the NGOE nationally for all CMOs funded to provide mental health services thereby increasing analysis, and supporting opportunities for service providers and other stakeholders to share information
3. Support a consistent use of a range of validated and reliable outcome measures that are collected and considered, with greater value achieved with a broader focus on outcomes rather than only outputs and activities
4. The integration of, and access to different types of data to be used by a range of stakeholders, including CMO peak bodies in NSW
5. Offer enhanced data reporting that can be used at a CMO, regional and national level to assist with monitoring service delivery to individuals, inform service planning and benchmarking activity[38] and enhance quality improvement initiatives
6. Enable a broader view of comparative data across LHDs and CMOs both at a regional and state level
7. Consideration of the inclusion of other reporting requirements where relevant to CMOs for example outcomes assessments and opportunities for service improvement

As more investment is made in the sector by Governments and other funders, it is critical to have reliable information and data with which to plan, resource, analyse, manage and support strategic decision making and service provision that is based on best practice and continuous quality improvement.[39]

---

[38] This is in line with the current benchmarking that occurs in NSW with Local Health Districts in relation to Adult Non Acute Inpatients, Adult Services and Child and Adolescent Acute Inpatient and Ambulatory Services with regular forums held to discuss data and improve decisions of care.

[39] MHCC Data Management Strategy 2011 Executive Summary, page 2

References

Australian Government Productivity Commission, *Contribution of the Not-For-Profit Sector, Research Report*, Canberra, January 2010, p. LV1

Australian Institute of Health and Welfare 2011, *Mental Health Non-Government Organisation Data Development Project, Phase 1* – Final Report Canberra

Australian Institute of Health and Welfare, METeOR (Metadata Online Registry) *Mental health non-government organisation establishments NBEDS 2015* http://meteor.aihw.gov.au/content/index.phtml/itemId/494729

Australian Mental Health Outcomes and Classification Network and Community Mental Health Australia 2013, *National Community Managed Organisation (CMO) Outcome Measurement Project: Final Report to the Mental Health Information Strategy Standing Committee* v1.1 AMHOCN, Sydney NSW

Australian Mental Health Outcomes and Classification Network and Community Mental Health Australia 2015, *Implementing Routine Outcome Measurement in Community Managed Organisations*, AMHOCN, Sydney, NSW

Australian Commission on Safety and Quality in Health Care 2014, *Scoping Study on the Implementation of National Standards in Mental Health Services*, Sydney, ACSQHC

Callis Z, Flatau P & Seivwright A 2017, *Progress in Outcomes Measurement: Findings from the Second Annual Outcomes Measurement in the Western Australian Community Sector Survey Bankwest Foundation Social Impact Series, No. 8*, Bankwest Foundation, Western Australia www.csi.edu.au/media/Bankwest_Social_Impact_Series_8_Final.pdf

Commonwealth of Australia 2016 *Open government data and why it matters: A critical review of studies on the economic impact of open government data*, Department of Communications and the Arts, February 2016

Flatau P, Zaretzky K, Adams S, Horton A & Smith J, 2015 *Measuring Outcomes for Impact in the Community Sector in Western Australia, Bankwest Foundation Social Impact Series No. 1*, Bankwest Foundation, Western Australia www.csi.edu.au/media/uploads/BankwestSocialImpactSeries-measuring-outcomes_aO5S3au.pdf

Government of Western Australia, Mental Health Commission 2015-2016, *Evaluation of the Mental Health Non-Government Organisation Establishment Reporting System* www.mhc.wa.gov.au/media/1605/ngoe-evalution-report-2015-16.pdf

Government of Western Australia 2017/18 *Mental Health Commission Contract Acquittal Data Collection* (MH CADC) Version 10.0

Government of Western Australia, Mental Health Commission 2015 *Western Australia Mental Health Non-Government Organisation Establishment In-Brief 2013-2014* www.mhc.wa.gov.au/media/1608/western-australian-non-government-organisation-__establishment-_-in-brief-2013-14-2.pdf

Kelly PJ, Deane FP, Baker AL, & Keane CA, *Client Outcomes Management System (COMS): data report 2013*, 1Illawarra Institute for Mental Health, School of Psychology, University of Wollongong, Wollongong http://www.nada.org.au/media/61445/coms_data_report_2013___final_.pdf

Mental Health Commission of NSW 2014 *Living Well: A Strategic Plan for Mental Health in NSW*, NSW Mental Health Commission https://nswmentalhealthcommission.com.au/sites/default/files/Living%20Well%20-%20A%20Strategic%20Plan%20full%20version.pdf

Mental Health Coordinating Council 2016 *Member Consultation Briefing Note, Community Managed Mental Health Sector Development Plan/Strategy*, May http://www.mhcc.org.au/wp-content/uploads/2018/05/20160516nswcmosdstrategy-memberconsultation___1_.pdf

Mental Health Coordinating Council 2010 *Data Management Strategy Report October Phase 1* http://www.mhcc.org.au/wp-content/uploads/2018/05/mhcc-data-mgt-strategy-ph1-report-2010.pdf

Mental Health Coordinating Council 2010 *NSW Community Managed Mental Health Sector Mapping Report* http://www.mhcc.org.au/wp-content/uploads/2018/05/mhcc-sector-mapping-report-2010.pdf

Mental Health Coordinating Council 2008 *NGO Development Strategy: Mental Health 2004-2007 Final Report* http://www.mhcc.org.au/wp-content/uploads/2018/07/final-report-ngo-development-strategy11-20081.pdf

NADA (Network of Alcohol & other Drug Agencies) 2009 *A Review of Screening, Assessment and Outcome Measures for Drug and Alcohol Settings*, www.nada.org.au/media/17954/nada_review_of_tools_and_measures_final_apr09.pdf

NADA 2011 *NGO Drug and Alcohol and Mental Health Information Management Project Pilot Evaluation* Report www.nada.org.au/media/16269/nada_damh_info_man_pilot_eval_report.pdf

NADA 2015 *Data Dictionary and Collection Guidelines for the NSW MDS for Alcohol Treatment Services* NSW Health NSW MDS Data Dictionary

NADA, 2012 *Dictionary and Collection Guidelines for the NMDS for Alcohol Treatment Services* AIWH NMDS Data Dictionary

NSW Ministry of Health 2017 *Health Systems Information and Performance Reporting, Mental Health Community Managed Organisations: Experiences, Resources and Activity (CMO-ERA) Project, Project Plan* 23/7/17, v1.0

Queensland Department of Health 2017/2018 *Mental Health Non-Government Organisation Establishment Data Collection (MH NGOE DC) User Guide*

Queensland Department of Health 2015 *Mental Health Non-Government Organisation Establishment Data Collection (MH NGOE DC) Specifications and Data Guide*

Seivwright A, Flatau P, Adams S & Stokes C 2016 *The future of outcomes measurement in the community sector, Bankwest Foundation Social Impact Series,* No. 6, Bankwest Foundation, Western Australia www.csi.edu.au/media/uploads/Social_Impact_Series_6.pdf

Smith-Merry J, Hancock N, Bresnan A, Yen I, Gilroy J, Llewellyn G 2018 *Mind the Gap: The National Disability Insurance Scheme and psychosocial disability. Final Report: Stakeholder identified gaps and solutions*. University of Sydney: Lidcombe http://sydney.edu.au/health-sciences/documents/mind-the-gap.pdf

Appendix A - Outcome Measures

Outcome measures are an invaluable tool to highlight an individual's recovery progress, and can include questionnaires, tools, instruments or scales. Outcome measures also provide an opportunity to demonstrate change over time. It is understood that the collection of routine outcome measures enhances CMOs ability to ensure a person led approach, consider data based on individual progress and identify areas for additional support, provide an opportunity for benchmarking, and improve the quality of service provision.[40]

CMOs in NSW are undertaking a number of steps to ensure consistent outcome measurement use. Outcome measures are collated at an organisational level with data produced for tenders and planning. Organisations may also use the information to understand how specific population groups are presenting, or have changing needs, and can be used to contribute to funding requirements and accreditation processes.

On its website, the Australian Mental Health Outcomes and Classification Network [41] identifies the importance of outcome measures in improving the quality of care and mapping the recovery journey.

The following outcome measurements were recommended in *the Implementing Routine Outcome Measurement in CMOs Report* 2015 as the most appropriate tools in most situations for community managed organisations delivering mental health services in Australia. The tools were chosen for their ease of use, no cost, reasonable psychometric properties, and appropriateness for the community sector and completion by the people with lived experience. The report also identified that '*a single tool would not be sufficient to cover the diversity of outcomes achieved by the sector.*'[42]

---

[40] Callis et al, 2017 identified the most common reasons CMOs find outcome measurement important were linked to organisational objectives such as seeking to improve services, planning and strategy

[41] At: www.amhocn.org/resources/frequently-asked-questions

[42] Australian Mental Health Outcomes and Classification Network and Community Mental Health Australia 2015 Implementing Routine Outcome Measurement in Community Managed Organisations, page 6

Table 1: Outcome Measurements Recommended in the Implementing Routine Outcome Measurement in CMOs Report 2015

Area covered	Recommended Outcome Measure
Recovery	Recovery Assessment Scale (RAS) or Stages of Recovery Instrument (STORI)
Thoughts and Feelings	Kessler-10 (K-10) or Carer QoL or Strengths and Difficulties Questionnaire (SDQ)
Daily Living and Maintaining Relationships	Work and Social Adjustment Scale (WSAS)
Social Inclusion	Living in the Community Questionnaire (LCQ)
Quality of Life	World Health Organisation Quality of Life – Brief Australian Version (WHOQoL-BREF)
Experience of Service	Your Experience of Service (YES) or Carers Experience of Service (CES)
Multi-Dimensional	Camberwell assessment of Need – Short Appraisal Scale (CANSAS)

This report notes that the NSW Mental Health Branch are presently reviewing the outcome measurement tools mandated under current contracts, with the expectation that just one of the mandated tools will suffice as a measurement tool. This will then be consistent with the recommendations from the Commonwealth arising from the Fifth National Mental Health Plan. That tool is likely to be the Living in the Community Questionnaire (LCQ). The Commonwealth sees the LCQ as both brief and sensitive to change and has capacity for further development. Importantly, it could be used across Australia for comparable benchmarking with a particular emphasis for community settings and community managed organisations.

Please see Appendix B, Review of Outcome Measures Used in NSW for specific information.

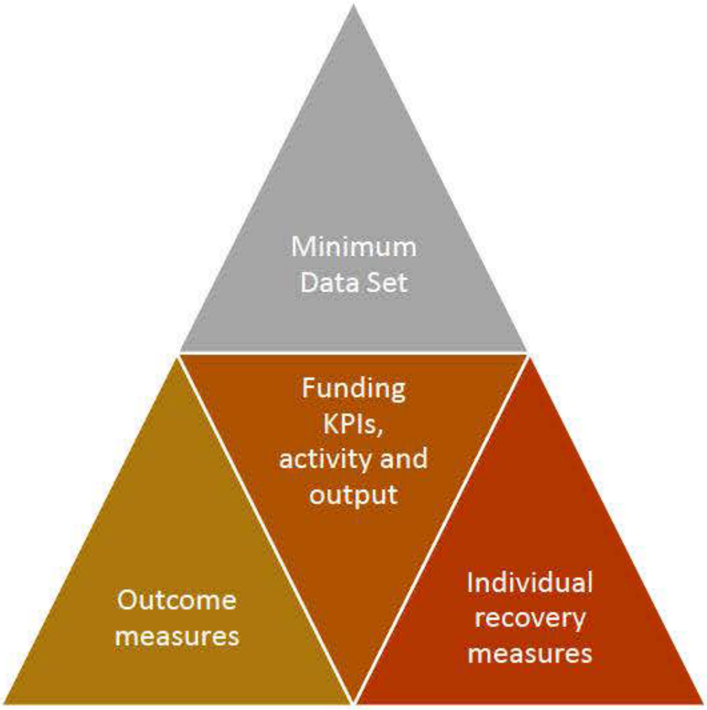
At this point in time the Centre for Social Impact at the University of Western Australia is conducting an independent research on outcomes measurement practice in the Australian community sector (2018). This is the inaugural national Outcomes

Measurement in the Community Sector Survey, replacing the Outcomes Measurement in the WA Community Sector Survey, which has run annually since 2015.[43] Previous work has had a significant impact to the WA community sector in terms of increasing the understanding of outcomes measurement practice in the community sector, adding a focus on measuring outcomes and the setting of policy.

The survey asked basic details about an organisation, e.g. number of staff, assets and liabilities; type of organisation; how the organisation measures its outcomes; facilitators, barriers and challenges to outcomes measurement; the organisation's mission, vision and values, and how state/territory-specific policy affects the organisation's outcomes measurement.[44]

Diagram 2 below highlights the complexity for CMOs in their collection of data for individual, funder and organisational use.

Diagram 2: Existing data collection schism for CMOs



---

[43] Reports can be found at: www.csi.edu.au/search/?q=social+impact+series

[44] Survey information received by MHCC on 8/2/18

Appendix B - CMO Outcome Measures Used in NSW

NSW Program	Camberwell Assessment of Need Short Appraisal Schedule (CANSAS)	Life Skills Profile (LSP)	Recovery Assessment Scale – Domains and Stages (RAS-DS)	Living in the Community Questionnaire (LCQ)	Quality of Life (QOL)	Activity and Participation Questionnaire (APQ6)	Depression Anxiety Stress Scales (DASS)	Kessler 10 (K10)	Carer Star
1. Community Living Supports (CLS)				√					
2. Youth Community Living Supports (YCLS)	√		√			√			
3. Family and Carer Mental Health Program									√
4. Housing and Accommodation Support Initiative (HASI)				√					
5. Housing and Accommodation Support	√		√	√					

NSW Program	Camberwell Assessment of Need Short Appraisal Schedule (CANSAS)	Life Skills Profile (LSP)	Recovery Assessment Scale – Domains and Stages (RAS-DS)	Living in the Community Questionnaire (LCQ)	Quality of Life (QOL)	Activity and Participation Questionnaire (APQ6)	Depression Anxiety Stress Scales (DASS)	Kessler 10 (K10)	Carer Star
Initiative Plus (HASI Plus)									
6. LikeMind			√					√	
7. Resource Recovery Support Program (RRSP)	√	√	√	√					
8. Supported Accommodation		√	√		√				

Note: CMOs may use other outcome measures to the above lists in their support of individuals, families and carers.

* The Family and Carer Mental Health Program has recently mandated through the Key Performance Indicators that CMOs complete the DASS and one other.

Appendix C - Comparison of NMDS Service Taxonomy

The Project's aim is to scope the feasibility of implementing a National Minimum Dataset for Mental Health Establishments (NGOE) with NSW CMOs that provide NSW Government funded mental health support services. The scope of the Mental Health Non-Government Organisation Establishments National Best Endeavours Data Set (MH NGOE NBEDS) is mental health-related non-government organisations that provide one or more of the service types included in the service taxonomy.

The following table shows a comparison of the National Minimum Data Set and the service taxonomy used in Western Australia and Queensland.

Table 2: Comparison of NMDS Service Taxonomy

	NMDS Taxonomy	METeOR page #	Western Australia 2013	Queensland 2017
1.	Care coordination	4		✓
2.	Counselling - face-to-face	7	✓	✓
3.	Counselling, support, information and referral - online	5		✓
4.	Counselling, support, information and referral - telephone	6	✓	✓
5.	Education, employment and training	8	✓	✓
6.	Family and carer support	9	✓	✓
7.	Group support activities	10	✓	✓
8.	Individual advocacy	11	✓	✓
9.	Mental health promotion	13	✓	✓

	NMDS Taxonomy	METeOR page #	Western Australia 2013	Queensland 2017
10.	Mental illness prevention	14	✓	✓
11.	Mutual support and self-help	15	✓	✓
12.	Personalised support - linked to housing	16	✓	✓
13.	Personalised support - other	17	✓	✓
14.	Sector development and representation	18	✓	✓
15.	Self-help—online	19		✓
16.	Service integration infrastructure	20		✓
17.	Staffed residential services	21	✓	✓
	Total		**13**	**17**

Appendix D – Data Collection Items for Drug and Alcohol Services

The following specifies the data collection for each data item.

Commencement of Service Episode - These items should be completed on the day of the initial assessment

Administrative data items	*Person Identifier (Client Code)*
Client data items	Date of Birth Date of Birth Status Sex Aboriginal and Torres Strait Islander Origin Country of Birth Preferred Language Principal Source of Income Living Arrangement Usual Accommodation
Drug use data items	*Client Type* Principal Drug of Concern/Gambling Method of Use for Principal Drug of Concern Other Drugs of Concern/Gambling Injecting Drug Use
Service data items	*Service Delivery Setting* Date of Commencement of Service Episode Postcode of Residence at Commencement of Service Episode Source of Referral to Service Previous Services Received Main Service Provided

During Service Episode

Drug use data items	*Other Drugs of Concern/Gambling*
	Previous Services Received
	Other Services Provided
	Service Contact Dates
	Postcode of Service Contact

Cessation of Service Episode - These items should be completed within 3 days of the date of the cessation

Service data items	*Date of Cessation of Service Episode*
	Reason for Cessation of Service Episode
	Referral to Another Service

Mental Health Establishments (NGO-E) Data Collection and Broader Community Managed Organisations Reporting Requirements in 2018-19 Scoping Study

Project Report 2 – 2019

mhcc
mental health coordinating council

Mental Health Coordinating Council

Building 125, Corner of Church & Glover Streets Lilyfield NSW 2040
PO Box 668 Rozelle NSW 2039

For further information please contact:

Carmel Tebbutt
Chief Executive Officer

Julie Millard
Project Lead / Consultant in Mental Health

The project is an initiative of the Mental Health Coordinating Council, funded by the NSW Ministry of Health.

MHCC acknowledge the Australian Aboriginal and Torres Strait Islander peoples as the first inhabitants of the nation and acknowledge the traditional custodians of the lands where we live, learn and work.

MHCC values the lived experience of people recovering from mental health conditions both past and present.

Please cite this paper as follows:

Mental Health Coordinating Council (MHCC) 2019, *Mental Health Establishments (NGO-E) Data Collection and Broader Community Managed Organisations Reporting Requirements in 2018-19 Scoping Study Project Report*, MHCC, Sydney Australia.

Table of Contents

Acknowledgements

MHCC acknowledge and thank the NSW Ministry of Health for its support of this scoping study. MHCC also thank the many supporters and contributors from community managed organisations who engaged in consultations and provided valuable information to the project.

This report is to be read in conjunction with the MHCC's Report: *Implementing the National Minimum Dataset for Mental Health Establishments (NGOE) in NSW Community Managed Organisations: Scoping Study Project*, June 2018.

The recommendations for NGO-E implementation in NSW from this previous report are included at Appendix A

Acronyms

AIHW	Australian Institute of Health and Welfare
CES	Carer Experience of Service questionnaire
CLS	Community Living Supports
CMO	Community managed / non-government organisation [1]
CMO-ERA	Community Managed Organisations Expenditure, Resources and Activity
HASI	Housing and Accommodation Support Initiative
InforMH	Information for Mental Health
LHD	Local Health District
METeOR	Metadata Online Registry
MHCC	Mental Health Coordinating Council
MH NGOE NBEDS	Mental Health Non-Government Organisation Establishments National Best Endeavours Data Set
MH NGOE NMD	Mental Health NGO Establishments National Minimum Data Set
NDIS	National Disability Insurance Scheme
NMDS	National minimum data set
NGOE	Non-Government Organisation Establishment
PHN	Primary Health Network
YES	Your Experience of Service questionnaire
YCLS	Youth Community Living Supports

---

[1] ACSQHC Scoping Study on the Implementation of National Standards in Mental Health Services 2014 pg. 7. ‘The terms ‘community-managed organisation’ (CMO) and ‘community-managed sector’ refer to non-government organisations providing services to people with mental health issues. These terms have been adopted as the preferred terms by representative bodies in the sector.’

Executive Summary

The Mental Health Coordinating Council (MHCC) has been supported by NSW Health to conduct a project to scope the feasibility of enhanced data collection for Community Managed Organisations (CMOs) in NSW.

The Stage 1 report of this project provided a history of CMO data collection and information on a dynamic sector landscape, including mental health funded programs and contractually required outcome measures in NSW. The report discussed the benefits and challenges of CMO data collection including service types and taxonomy use comparison, an overview of data collection in other states and jurisdictions relevant to the CMO sector and compared it to the National Minimum Data Set (NMDS) taxonomy.

Stage 2 of the CMO Expenditure, Resources and Activity project set out to enhance the reporting of data on activity and expenditure in the sector and determine the best practice approach to implementation of collection of the NGO-E within NSW CMOs

MHCC has a key role in ensuring there is quality CMOs data collection in NSW and to support a best practice approach to implementing the Mental Health NGO-E National Best Endeavours Dataset 2015 (NGO- E). The NGO-E has been developed as a national standard for an annual collection of data on activity, expenditure and staffing from CMO services.

Findings from CMO consultations confirmed that CMOs are supportive of consistent quality data collection that meaningfully adds to and demonstrates the value of the mental health CMO sector. CMOs are keen that all levels of Government include the NMDS in their contracts with CMOs, so as to reduce their data burden. Consultations also identified that the challenges in data collection does not prevent CMOs from developing services, as CMOs are flexible and respond to emerging needs within contractual parameters. However, there remain issues with the inconsistency, lack of relevancy and quality of the data.

MHCC is keen to ensure that information from the consultations and issues for the CMO sector inform further stages of this project.

Purpose of the NSW NGO-E Scoping Study Project

Mental Health Coordinating Council (MHCC) has partnered with the Mental Health Branch and the Health System Information and Performance Reporting Branch of NSW Health since 2010 to support enhanced data collection for Community Managed Organisations (CMOs) services in NSW. MHCC will continue to play a key role in ensuring there is quality data collection by NSW CMOs and in the support of a best practice approach to implementing the Mental Health Non-Government Organisation Establishments National Best Endeavours Dataset 2015 (NGO- E) in the future.

The NGO-E has been developed as a national standard for an annual collection of data on activity, expenditure and staffing from CMO services.

The report of Stage 1 of this project[2] provided information about:

- the changing community managed sector landscape
- a history of CMO data collection
- the benefits and challenges of NSW CMO data collection
- service types and taxonomy use and comparison of NMDS service taxonomy
- the NGO-E in other states and territories and other data collections relevant to community managed mental health services
- the CMO contractually required outcome measures used in NSW.

Stage 2 of the joint CMO Expenditure, Resources and Activity project has set out to enhance the reporting of data on activity and expenditure in the sector and determine the best practice approach to implementation of collection of the NGO-E in scope with NSW CMOs.

The project has broadened the scope of the NGO-E to assess the feasibility of consolidating the performance monitoring collections, while supporting the Mental Health Branch to progress the NGO-E work by reviewing the current contractual data collection for mental health funded services in NSW, to better understand opportunities for alignment with the NGO-E.

Right from the start of the project there is clear interest and broad support from NSW CMOs in the implementation of the NGO-E. However, scoping was needed before implementation could be planned in detail. The CMO NGO-E Scoping Study Project was managed by MHCC.

The objectives and deliverables of the NGO-E Project were to:

- Facilitate a consultation workshop with CMOs in NSW that included discussion of the proposed roll-out of the YES and CES questionnaires
- Conduct a confidential review of current contractual data collection for mental health funded services in NSW, to better understand opportunities for alignment with the NGO-E
- Identify issues for contractual variation

---

[2] MHCC, Implementing the National Minimum Dataset for Mental Health Establishments (NGOE) in NSW Community Managed Organisations: Scoping Study Project Report, June 2018

- Consult with Victorian Health Services to determine their implementation
- Provide a mid-project report (September 2018)
- Provide a final report (December 2018) that discussed findings

Process

The project required a process that included:

- Consultation with the NSW Ministry of Health NGO-E and YES/CES Projects Steering Group to confirm the project outline and approach
- A CMO NGO-E Scoping Study Project Plan to be developed and approved by MHCC Board
- A review of relevant documentation necessary to inform the project, including the context for comparison of approaches and analysis of information and issues
- Consultation with CMOs and other identified key stakeholders
- Presenting and updating members at the NSW NGO-E and YES/CES Projects Steering Group with feedback sought on process of project
- The Consultation Workshop undertaken
- Completing the Project Report and recommendations.

Timeframe

The initial scoping study was completed by December 2018. The second stage of the scoping study was completed in February 2019.

Project Parameters

MHCC undertook the project with the understanding that consistent data collection can assist with the identification of gaps in service provision and demonstrate the value of the CMO sector, while acknowledging there is a need to ensure quality of data and reduction of the data burden for CMOs.

The six-month project included the following activities:

1. NSW NGO-E and YES/CES Projects Steering Group meetings
2. Consultations with CMOs
3. CMO Consultation Workshop
4. Consideration of CMO Service Types and Metadata Items
5. Confidential mapping of NSW CMO mental health funded programs data collection requirements against the National Minimum Data Set (NMDS)

1..

YES and CES Project

MHCC supports the collection of information and data from people with lived experience, their families and carers about their experiences of mental health services through the YES and CES questionnaires. A number of CMOs have indicated they are already using the YES questionnaire in NSW. All CMOs who were consulted are supportive in principle to pilot the CMO YES and CES questionnaires. A working group has been established with MoH, MHCC and interested CMOs to provide advice on designing the pilot.

The Your Experience of Service (YES) and the Carer Experience of Service (CES) project for NSW Mental Health CMOs will build on the knowledge, infrastructure and systems of the implementation for YES and CES in the NSW public mental health sector. The YES questionnaire was developed nationally to measure individual's experience of care whilst accessing an inpatient or community mental health service. It was released for use in public mental health services in 2015. In 2017 the CMO-YES was released and is broadly consistent with the public service version. There have been minor changes to the wording and some questions to better suit the CMO sector.[3]

The Mental Health CES was developed nationally to gather information about a carer's experiences of services. It was released for use in both public sector services and CMOs in early 2017. The survey uses the same domain structure and similar questions as YES and CMO-YES making it possible to make comparisons between consumer and carer experiences of the same services. The CES was rolled out in NSW public mental health services in 2018. It was implemented using the same methodology as YES. Initially the questionnaire will be available as a paper-based form. A project to develop an electronic version will commence in late 2018–19.

Resourcing for the CMO YES and CES project is through the InforMH, a team of the System Information and Analytics branch of NSW Health. The CMO YES and CES Project Working Group has been established to consider and support implementation. The CMO YES questionnaire will be piloted with interested CMOs, in 2019 with an evaluation to occur after 12 months to inform how the questionnaire could be more broadly implemented in the CMO sector. The roll out stage for the CES questionnaire will commence in late 2019.

National Mental Health Service Planning Framework

The National Mental Health Service Planning Framework (NMHSPF) estimates the activity and resources needed to meet population-based mental health service demand. The Fifth Mental Health Plan recognises the tool as a mechanism for guiding planning and resource allocation in a nationally consistent manner.

NGO-E data could complement the NMHSPF and assist in planning for service growth in the future, specifically:

- The NMHSPF shows the need to grow community services and efficient reconfiguration of bed-based services rather than solely increasing acute inpatient services.

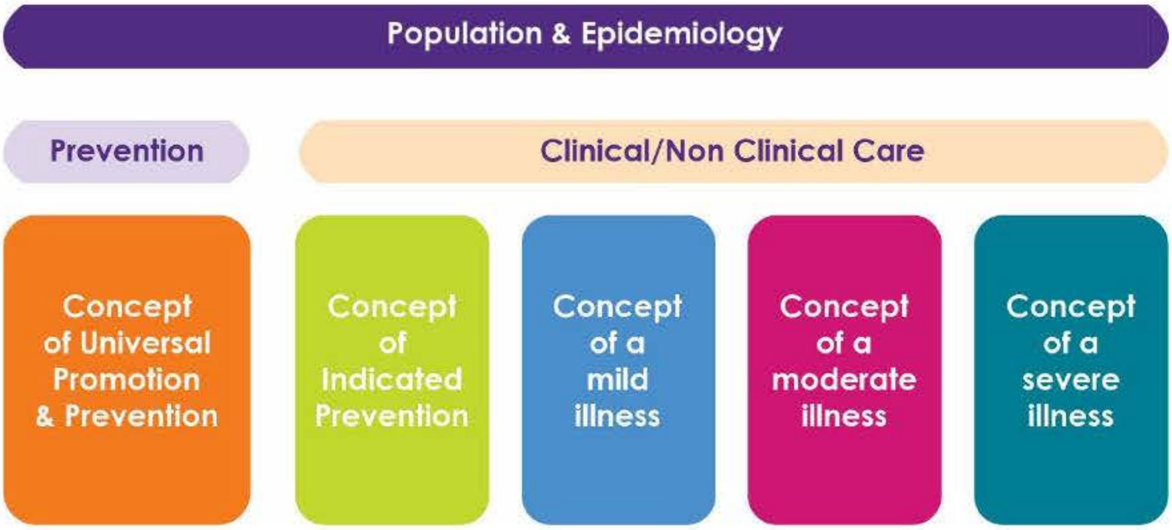
---

[3] Further information about the development of the questionnaires is at: https://www.aihw.gov.au/reports/mental-health-services/mental-health-services-in-australia/national-mental-health-committees/mental-health-information-strategy-standing-committee/your-experience-of-service-survey-instrument

- LHD planning must consider the broader spectrum of inpatient services.
- This planning *also* involves considering how some bed-based services could be delivered through CMO partnerships or services (such as step up/step down, aged care partnerships, and community residential).

The NMHSPF can model the resources needed to meet demand.

- For CMOs, modelled resources include:
  - Workforce FTE
  - Client-related staff hours
  - Occasions of service by staff
  - Estimates can be identified by Local Health District or Local Government Area
  - Estimates become more reliable at larger geographies
  - Estimates can be separated between funding source, including identifying those that should be provided by CMOs
- Estimates can be separated by age group
- The types of services provided by CMOs in the NMHSPF model were decided through extensive consultation with clinicians
- Models care packages of best-practice care for individuals with different mental illness and severity levels form the basis of the modelling



- Robust modelling relies on parameters of supply and demand figures being aligned (e.g. the same definitions of client contacts)
  - It is imperative that the NGO-E outputs can be compared with NMHSPF estimates.

The Mental Health Coordinating Council recommends that consideration be given to the following:

- Potential for all data to be submitted to MoH via a portal not just NGO-E
- Concerns about the burden on CMOs for implementation
- Consider a staged implementation by program (e.g. CLS)

- Resource implications for implementation

CMOs want to enter data once and use it often. In this 21st century of technology that shouldn't be hard.

CEO during CMO consultations

2. Project Consultation

a. Consultation with CMOs

MHCC ensured a diverse range of opinions were sought from CMOs in NSW through additional consultation. Consultation was by face to face interview or via telephone and organisations were selected based on:

- Organisations that receive NSW mental health funds from the various funding streams
- Extensive experience in the health and community sectors
- CMOs that cover metropolitan and regional/rural areas
- Cover the range of service types as identified in the taxonomy
- Provision of multiple data collection
- Priority areas for mental health services in NSW
- Organisations that did not complete the CMO Data Collection Survey during Stage 1 of the project
- Invited organisations that would not be attending the CMO Consultation workshop.

A range of CMOs were consulted, i.e. six face to face and four by telephone, with the consultations taking approximately 2-3 days.

Consultations with rural or regional CMOs occurred via telephone from the MHCC office.

The objectives for consultations with CMOs was to provide an opportunity for discussion and consideration of the following points:

1. Identification of issues when developing processes for data collection, submission, validation and reporting
2. Options for staging NGO-E and YES/CES implementation with NSW CMOs and feedback on collection, storage and reporting issues
3. Understanding the likely capacity of NSW CMO services to provide annual NGO-E data, including the consideration of sectors or regions with greater or lesser capacity
4. Likely practical issues in implementing data collection, including clarity of the NGO-E data items
5. Potential alignment of current NSW mental health funded CMOs to the service taxonomy proposed within NGO-E
6. Understanding the capacity and willingness of the CMO sector for experience measurements i.e. the YES and CES surveys, and to inform the set-up phase.

The Project Lead for MHCC was responsible for liaison, communication and scheduling appointments with provider organisations, and the development of questions in relation to NGO-E implementation.

The consultations with CMOs commenced on 11 September 2018, and concluded by 24 September 2018 so as to avoid a clash with World Mental Health Day on 10 October and Mental Health Month activities by CMOs.

An overview of the findings from the consultations with CMOs confirmed that CMOs are supportive of consistent quality data collection that is meaningful that adds value to the mental health sector. A number of CMOs identified they are collecting more data than is required by funders as this enhances service provision, provides an opportunity to identify gaps, for own reporting mechanisms and to identify quality improvement activities. As one CEO advised: "*We have had an emerging and evolving set of data collection. This has led to an emphasis on equitable distribution of services across rural, regional and metropolitan areas.*"

In NSW three CMOs (Flourish Australia, Neami and Mission Australia) were involved in the implementation of the NMDS in Western Australia and Queensland.

CMOs are keen that the Mental Health Branch encourages and supports Local Health Districts and Health Networks to include the national minimum data set in their contracts with CMOs, so as to reduce their data burden.

CMOs who were consulted agreed that collecting data on peer workers was an important step forward for recovery oriented service provision.

CMOs identified that the challenges in data collection does not prevent CMOs from developing services, CMOs are flexible and respond to emerging needs within contractual parameters. CMOs reported that as they are often capturing multiple data collections for varying funding bodies they do not envisage any problems with accommodating the NMDS into their current databases. All CMOs agreed that a web portal is the most efficient system of data entry.

The HASI/CLS data collection was reported as more comprehensive and sophisticated and could easily accommodate the NMDS.

There remain issues with the inconsistency, relevancy and quality of the data being requested. Opinions differed about the NMDS with some stating it will streamline data collection whilst others reported that the NMDS would not add any value to the organisation, or the CMO sector to inform the work being undertaken.

The following comments from the consultations highlight additional issues for the CMO sector:

- The current funding models were described as flawed as the collection of data, particularly on episodes of care does not consider holistic health care and whole of life support and service provision by CMOs
- Data collection does not show the effectiveness of CMO interventions
- Data Collection is often driven by funding rather than service requirements

- There needs to be greater clarity and consistency on standards and the key performance indicators required, with each funded program differing greatly in their requests for information
- Key performance indicators are often just global stats, nothing specific
- Episodes of care data collection is not consistent with the social and emotional wellbeing model with a lot of support services going unrecognised
- Data collection is focused only on the individual and not the family of the community and the wrap around support that is often required
- The NMDS does not consider sexuality or gender indicators e.g. LGBTIQA[4]
- Primary Health Networks are funding CMOs for small sums of money, often with it not equitable in terms of data reporting for the amount of investment required
- There is inconsistency in data collection requirements for a number of CMOs who are providing services in other states and territories, or for Primary Health Networks
- Data collection can also be problematic for a CMO when engaged in a partnership with a Local Health District
- The different data requirements and methodology of data systems has an impact on the ability for CMOs to produce quality comprehensive reports
- It is essential that there is one single portal that is able to link with existing CMO databases, rather than have CMOs create another system to comply
- There were identified differences in the amount of information and reports CMOs receive back from the Ministry of Health with some CMOs advising of irregular reporting, reports only on funds and staffing and information that does not enhance service provision
- The use of outcome measures continues to be problematic, with some funding grants requiring use of one or two of them, while other grants do not require any. Some outcome measures are asked for quarterly, while others are bi-annually. CMOs advised they are using a number of outcome measures as identified in the previous MHCC report.[5]

A list of CMOs involved in the consultations, their funding stream and service type are at Appendix B:

b. CMO Consultation Workshop

A *CMO Consultation Workshop* was held on 16 November 2018 at the Harbour View Hotel in North Sydney, providing an opportunity to garner CMO sector and NSW Health expertise, representation and discussion of issues.

The workshop had a duality of purpose and provided participants the opportunity to discuss and consider: the NGO-E, service types, contractual arrangements, any issues

---

[4] LGBTIQA - Lesbian, Gay, Bisexual, Transgender, Intersex, Queer or Asexual. ACON Health Outcome Strategy 2013-2018 Mental Health and Wellbeing has a strong focus on data and its role. Strategy available at: https://www.acon.org.au/wp-content/uploads/2017/02/HOS-Mental-Health.pdf

[5] MHCC, Implementing the National Minimum Dataset for Mental Health Establishments (NGOE) in NSW Community Managed Organisations: Scoping Study Project Report, June 2018, Appendix C – Outcome Measures p.54 (not available online)

with implementation, the YES/CES questionnaires and their proposed roll-out and view a demonstration of the WebSurvey portal used in Western Australia.

Member attendance of the workshop covered the range of service types as identified in the taxonomy[6]. The Workshop was co-facilitated by InforMH and MHCC. Sixteen primary CMOs identified that they provide or may provide HASI/RRSP, CLS, LikeMind, FCMHP or other specific mental health funded services in the future.

Thirty-eight people participated in the workshop.

Presentations were provided on the two projects, and the policy context for the NGO-E in relation to the 5th National Mental Health Plan, the National Mental Health Service Planning Framework and the National Mental Health Information Priorities, and the need for a national roll-out.

YES and CES Questionnaires

Information was provided on the history of public mental health services use of the YES questionnaire. Since 2015 70,000 YES surveys (available in multiple languages) have been completed primarily on a quarterly basis. The differences between public and CMO versions, the reporting structure, the experience of a Local Health District implementing the YES survey, the development of the Carer Experience of Service questionnaire and the proposed pilot of both surveys with CMOs in NSW were also discussed. Samples of the questionnaires were tabled for consideration.

The set-up for the YES questionnaire ensures CMOs are prepared to offer the survey while insuring there is infrastructure at the state level to support collection and reporting. Key milestones will include:

- Identifying which CMOs will participate in the pilot
- Developing a framework for using experience measurement
- Developing a protocol for offering the questionnaire
- Taxonomy of services including process for de identifying
- Artwork for the questionnaire
- Supporting materials for service users
- Supporting materials for services
- Scanning and data extraction
- Data storage
- Designing reports.

Slido[7] was used to provide an opportunity for real time consideration of issues and for participants to ask questions about the CMO YES and CES questionnaires. As a result of the consultations a YES & CES Working Group will be convened and the YES questionnaire will be piloted with volunteer CMOs in 2019.

---

[6] See Appendix C for CMO Service Types Summary

[7] Slido is an audience interaction tool for meetings, events and conferences. It offers interactive Q&A, live polls and insights from the audience www.sli.do

NGO-E

The history of CMO data collection and MHCC's advocacy for consistent and value-added data collection for the CMO sector was discussed. To support the NMDS collection, 17 service types for CMOs who receive mental health funds were developed. The CMO Service Types Summary of definitions and distinguishing features was tabled and is available at Appendix E p. 42. The *Mental Health Non-Government Organisation Establishments National Best Endeavours Dataset* (NGOE) is an annual collection of aggregate data on service funding, staffing and activity i.e. clients and contacts. It was developed throughout 2009- 2010 in consultation with the CMO sector.[8]

Presentation about the 17 CMO service types and the Australian Institute of Health and Welfare's METeOR the Metadata Online Registry[9] provided the link between service type and metadata required to be collected.

WebSurvey

Across Australia, Western Australia and Queensland have implemented a data collection system. NSW would be the third state/territory to do so. Both states procured the services of WebSurvey[10] as the organisation that developed and hosts the online data collection instrument. Access is by a secure webpage with a secure link emailed to the authority for each mental health service provider. There have been no major issues with implementation, due to ongoing CMO training and access to a helpdesk and support. Contracts include information on allocation of service type(s) and contract reporting requirements, data is due in June and December for Western Australia (WA) but quarterly in Queensland. A demonstration of WebSurvey, the reporting process, actual data collection, potential workflow and the evaluation and activity reports provided to the sector was presented by Trevor Dare, Manager Information Development, Performance and Programs Directorate WA Mental Health Commission.

The WebSurvey demonstration provided participants an opportunity to discuss the impact for a CMO that provides different service types; the software; the inability to add outcome measures as it is an aggregated system; resources, helpdesk and training provided; data use in planning of services, and the comparison on service performance for each service type.

Panel Discussion

A panel provided an opportunity for questions and discussion on the NGO-E, its impact

---

[8] MHCC NSW Community Managed Mental Health Sector Data Management Strategy Phase 1 Report, Oct 2010 https://www.mhcc.org.au/wp-content/uploads/2018/05/mhcc-data-mgt-strategy-ph1-report-2010.pdf

[9] METeOR – Australian Institute of Health and Welfare (AIHW) Metadata Online Registry http://meteor.aihw.gov.au/content/index.phtml/itemId/494729

[10] WebSurvey is an online survey, hosted in Melbourne and priced using a per-user model. Online survey set up costs begin at $2200 +GST and a usage fee of $1.50 +GST applies per respondent. Information from website on 6/3/18 www.websurvey.com.au/

and future implementation. It was recognised that NSW differs from other states in its diversity of funders and programs. There was agreement that there is a current focus on outputs and not outcomes, that performance monitoring processes are in place but that changes to contracts may take time with some standardisation of data collection currently occurring, and that benchmarking is useful but that it needs to reflect the work of all CMOs. There was discussion on who is the custodian of the data and how it will be used.

Changes and alignment in contracts and requisite data collection were deemed as essential to reduce data burden for CMOs. However, it was acknowledged that it would be beneficial for CMOs if other funding bodies for example, Family and Community Services also implemented the NGO-E. It was noted that CMOs are concerned that double collection of data may occur for their organisation, or that not all services being provided are being captured by the data collection.

It was understood from the consultations that the Mental Health Branch has four funding streams i.e. covering young people, adult and older persons all with various data collection requirements. For CMOs who provide a diversity of services this can result in the need for multiple databases.

c. Findings from Consultations

1. The Stage 1 Project Report and this report be made publicly available
2. That all mental health funded contracts in NSW be consistent with the NMDS and align with service types
3. CMOs are keen to streamline data collection and improve service provision. They recognise the need for consultation and liaison with the Mental Health Branch to identify and determine service types, especially given the diversity of services and then provide the NMDS for that service type and contractual funding arrangements.
4. The Aboriginal Health and Medical Research Council of NSW be involved in community-controlled sector awareness and information prior to any implementation of changes to required data collections for community-controlled organisations.
5. The use of the group work formula is problematic for CMOs and may benefit from a review.[11]
6. The NGO-E would benefit from linkage to the Mental Health Establishments data collection for public mental health services thereby providing consistency of data collection while supporting mapping of funds to activity
7. That the Mental Health Branch and InforMH provide clarity on the use of the NMDS for one-off project grants to CMOs who do not normally receive mental

---

[11] The current group work formula is: hours of group divided by 3.5 times number of attendees. Example: One group for 2 hours for 10 people = 3.5 hours. It is unclear what the rationale is for dividing by 3.5.

health funds, or those CMOs who receive mental health funds and Local Health District funds

8. InforMH to clarify that the taxonomy of services in the National Mental Health Service Planning Framework aligns with the NGO-E.[12]

Information from the consultations and issues for the CMO sector are being considered by MHCC in partnership with Mental Health Branch to inform an implementation phase.

---

[12] Minutes of NGO-E and YES & CES Project Steering Group Meeting 6/12/18

3. CMO Service Types and Metadata Items

A comparison of service types against the METeOR[13] metadata required was undertaken by the NGO-E Project Lead with it determined that there are few data items that are required to be collected by most service types.

The metadata items are:

- Source of funding
- ABN, identifier
- Program name
- Number of clients (receiving services), total
- Unique client count accuracy descriptor
- Total Australian currency
- Full time equivalent staff (paid)
- Hours worked by volunteer/unpaid staff
- Full-time equivalent staff paid peer workers
- Address

The majority of metadata items required for collection are specific to the service type. For example, additional items for Personalised Support – Other are: number of service contacts to individual clients, number of contact hours and outcome measurement tool indicator Yes/No/NA.

See Appendix D for the spreadsheet on Service Types and Metadata Items.

> **The national minimum data set does not include the opportunity to capture LGBTIQ+ or culturally relevant data. This is a serious gap in NSW and Australia's data collection.**
>
> Employee of a CMO during consultations

---

[13] METeOR AIHW's Metadata Online Registry http://meteor.aihw.gov.au/content/index.phtml/itemId/494729

4. Mapping of CMO Data Collection Requirements

To undertake the mapping review MHCC was provided with confidential specific information by Mental Health Branch that identified what data CMOs are currently required to collect based on the contracts of each of the mental health funded programs. This included but is not limited to the following:

- Key performance indicators
- Specific program data collection items
- Outcome measures
- Any other reporting requirements

Mapping of the current CMO data requirements against the NGO-E identified that there is not a significant burden for CMOs for the inclusion of data items into all new MoH funded contracts, variation to contracts or contract renewal. Duplication of data collection by CMOs would be avoided once contractual data was in line with the NGO-E. Consultation and negotiation with CMOs will support the allocation of CMO mental health programs to service types and with any contractual variation.

Appendix A: Recommendations for Future NGOE Implementation in NSW

MHCC Stage 1 Report *Implementing the National Minimum Dataset for Mental Health Establishments (NGOE) in NSW Community Managed Organisations: Scoping Study Project* identified that a successful CMO NGOE implementation in NSW requires commitment from government and CMOs and an integrated service delivery model.

The NSW CMO response to the implementation of the NGOE is considered to be favourable due to longevity and involvement in the pursuit of a minimum data set. As reported in the MHCC Annual Report in 2017: *For many CMOs the greater attention to agreed contracted KPIs is welcomed and will hopefully, as anticipated, provide stronger engagement with LHDs around activity and outcomes*.

CMOs understand the need for data and its benefits. However, the ultimate data goal for CMOs is to '*collect once and use often*'.

In 2011 when the MHCC Data Management Systems Business Plan was developed it was determined that a 'one solution for all' approach was not possible due to the technical and practical limits. However, portal-based technologies now permit centralised data collection with only a need for Internet access.

What will be required for implementation?

- A clear vision for NSW whereby data collection contributes to the improvement of health outcomes for all individuals who live with mental health conditions, their families and carers
- The determination of costs for set-up and implementation of CMO NGOE in NSW
- Stage 2 of the project to determine and support implementation of the NGOE for CMOs funded to provide mental health services
- Communication strategy that regularly consults with and informs the CMO sector about a proposed implementation of NGOE data collection
- Clear and concise information to CMOs about the roll-out, timeframe for implementation and expectations of data collection completion
- Access to a reliable and secure web portal for data collection and reporting
- Development (or modification) of a Data Dictionary and User Guide for NSW in relation to mental health funded services is required before implementation
- Realistic data collection periods[36] as determined in contract acquittals with data being accumulative.
- Reduction of data burden for CMOs. As reported in the WA Evaluation Report[37]: '...it is also evident that the needs for additional information need to be balanced against the level of reporting burden placed on organisations.'
- Data collection by programs as documented in contracts is in line with the NMDS to avoid duplication
- Recognition of the diversity of service delivery models within a service type.

- Clear and articulated definition of service types. For example, the WA Data Collection 3.1 states: 'It is the Mental Health Commission's responsibility to allocate the services they fund to a service type. Services will be allocated to a service type based on the principal function they are funded to provide. If an NGO is funded to provide one type of service, it can only be allocated to one service type. However, if an NGO is specifically funded to provide more than one type of service, the activity for each type of service should be collected under each relevant service type'[38]
- Consultation and negotiation with CMOs for all new contracts, variation to contracts or contract renewal in the allocation of CMO programs to service types
- Ongoing education, training and the nurturing of a culture of support via a Helpdesk for CMOs through MHCC, or InforMH at the Ministry of Health
- Provision of regular reports to CMOs and to the NSW CMO sector through the peak body

Recommendations

1. The national minimum data set be included in all contracts with departments, state and national programs that fund CMOs to provide support and other services – data that is collected once and used often. Appropriate support and training be provided to CMO's to ensure smooth implementation
2. Implementation of the NGOE nationally for all CMOs funded to provide mental health services thereby increasing analysis, and supporting opportunities for service providers and other stakeholders to share information
3. Support a consistent use of a range of validated and reliable outcome measures that are collected and considered, with greater value achieved with a broader focus on outcomes rather than only outputs and activities
4. The integration of, and access to different types of data to be used by a range of stakeholders, including CMO peak bodies in NSW
5. Offer enhanced data reporting that can be used at a CMO, regional and national level to assist with monitoring service delivery to individuals, inform service planning and benchmarking activity and enhance quality improvement initiatives
6. Enable a broader view of comparative data across LHDs and CMOs both at a regional and state level
7. Consideration of the inclusion of other reporting requirements where relevant to CMOs for example outcomes assessments and opportunities for service improvement.

Appendix B: Consultations with NSW CMOs

CMO	Funding stream	Service Type if known	Service Area	Date
Aboriginal Health and Medical Research Council of NSW (AHMRC), Surry Hills	Ministerial Approved Grants - Mental Health Statewide Coordination to support and develop the capacity of Aboriginal health services to deliver mental health services	Sector Development & Representation	NSW	11/9/18 Visit
ACON, Surry Hills	Suicide Prevention Fund	Sector Development & Representation	NSW	11/9/18 Visit
Mental Health Carers NSW, Woolloomooloo	Peak Body	Sector Development & Representation	NSW	11/9/18 Visit
Neami National, Hurstville	HASI / CLS	Personalised Support - Other	NSW	11/9/18 Visit
National Association for Loss & Grief NSW Inc., Dubbo	Other 2016-17 Grants – core funding	Counselling – face to face	NSW	19/9/18 T/c
Mental Health Coordinating Council, Lilyfield	Ministerial Approved & Other 2016-2017 Grants – for NDIS, LDU & peak	Sector Development & Representation	NSW	19/9/18 Visit
New Horizons, Ryde	HASI/CLS	Multiple	NSW	19/9/18 Visit
Centre for Rural and Remote Mental Health, Orange	Other 2016-17 Grants & Rural Adversity Mental Health Program (RAMHP)	Mental health promotion	NSW	20/9/18 T/c
Lifeline Australia	Ministerial Approved Grants - Crisis support telephone service	Counselling, support, information and referral - telephone	NSW	20/9/18 T/c

CMO	Funding stream	Service Type if known	Service Area	Date
Peer Support Foundation (Australia), Macquarie Park	Ministerial Approved Grants - Peer-led mentoring program supporting the mental, social and emotional wellbeing of young people	Mental health promotion	NSW	20/9/18 Visit
Flourish Australia, Sydney Olympic Park	HASI/CLS	Multiple	NSW	20/9/18 Visit

Organisations at CMO Consultation Workshop

Participants

ACI

Central Coast Local Health District

Flourish Australia

Grand Pacific Health

Independent Community Living Aust.

InforMH

Mental Health Carers NSW

Metropolitan Aboriginal Land Council

Mental Health Coordinating Council

Ministry of Health

Mission Australia

Mums and Kids Matter, Wesley Mission

Neami National

New Horizons

One Door Mental Health

Open Minds

Parramatta Mission

Sydney Local Health District

Sydney Women’s Counselling Service

WA Mental Health Commission

Wesley Mission

Appendix C: CMO Service Types Summary

The scope of the Mental Health Non-Government Organisation Establishments National Best Endeavours Data Set (MH NGOE NBEDS) is mental health-related non-government organisations which provide one or more of the service types included in the service taxonomy below. Mental health non-government organisations are private organisations (both not-for-profit and for-profit) that receive Australian and/or state or territory government funding specifically for the provision of services where the principal intent is targeted at improving mental health and well-being and delivered to people affected by mental illness, their families and carers, or the broader community. Services focus on providing well-being, support and assistance to people who live with a mental illness [and their families and carers] rather than the assessment, diagnostic and treatment tasks undertaken by clinically focused services. Following information from: http://meteor.aihw.gov.au/content/index.phtml/itemId/494729 See the *Service Types and Metadata Items* spreadsheet for information on actual metadata items required for each service type.

	Service Types	Definition	Distinguishing Features
1.	Counselling—face-to-face	Counselling services operate through a range of mediums including face-to-face, telephone and online. This service type is intended only for services providing face-to-face counselling. Counselling services provide a structured process that is concerned with addressing and resolving specific problems, making decisions, working through feelings and inner conflicts, or improving relationships with others (BAC 1986). Counselling facilitates personal growth, development, self-understanding and the adoption of constructive life practices. The counselling process will depend on the individual counsellor, the individual client and the specific issue.	• Delivered face-to-face • Primarily centre-based • Includes individual, family and group counselling *Inclusions:* • Talking therapies • Grief counselling • Relationship counselling *Exclusions:* • Counselling delivered in the context of other service types, e.g. Personalised support, carer support programs
2.	Counselling, support,	Counselling, support, information and referral services can be provided both via telephone and	• Delivered via telephone • Primarily delivered on a one-on-one basis

	Service Types	Definition	Distinguishing Features
	information and referral—telephone	online. This service type is intended only for those services provided via telephone. Counselling services provide a structured process that is concerned with addressing and resolving specific problems, making decisions, working through feelings and inner conflicts, or improving relationships with others (BAC 1986). Counselling facilitates personal growth, development, self-understanding and the adoption of constructive life practices. The counselling process will depend on the individual counsellor, the individual client and the specific issue. Mental health support, information and referral services are those that provide support for people experiencing mental illness and which offer reliable referrals, information and self-help resources to empower people to take steps towards maintaining mental health and emotional wellbeing (Lifeline 2012).	*Inclusions:* • Telephone crisis support • Helplines • Telephone counselling *Exclusions:* • Occasional services delivered under other service types that are incidentally provided via the telephone • Telephone support services that are delivered as an adjunct for other service types, e.g. after hours' carers support lines, warm lines • Counselling, support, information and referral services not provided by telephone
3.	Counselling, support, information and referral—online	Counselling, support, information and referral services can be provided both via telephone and online. This service type is intended only for services provided online. Counselling services provide a structured process that is concerned with addressing and resolving specific problems, making decisions, working through feelings and inner conflicts, or improving relationships with others (BAC 1986). Counselling facilitates personal growth, development, self-	• Primarily delivered on a one-on-one basis • Primarily delivered via an interactive 'chat' style modality *Inclusions:* • Synchronous online chat • Automated referral systems • Email Note: Email-based activity is not intended to be measured under the Mental health non-government organisation establishments DSS at this stage.

	Service Types	Definition	Distinguishing Features
		understanding and the adoption of constructive life practices. The counselling process will depend on the individual counsellor, the individual client and the specific issue. Mental health support, information and referral services are those that provide support for people experiencing mental illness and which offer reliable referrals, information and self-help resources to empower people to take steps towards maintaining mental health and emotional wellbeing (Lifeline 20	*Exclusions:* • Occasional services delivered under other service types that are incidentally provided via the Internet • Online services that are delivered
4.	Self-help—online	Self-help—online includes structured interactive online programs which take people, who have a lived experience of mental illness, through exercises to help them develop skills to handle life's challenges more effectively. Unlike Counselling, support, information and referral–online, services which fall under Self-help—online never involve interaction with another person, only interaction with the online program's content.	• Population-based (rather than individually-tailored) • Conducted online • Not individually facilitated by another person • Available 24 hours a day *Inclusions:* • Cognitive behaviour therapy- (CBT) based programs • Interpersonal psychotherapy- (IPT) based programs *Exclusions:* • Mutual support and self-help activities which incidentally occur online, e.g. online support groups (these services are not currently reported in the Mental health non-government organisation establishments DSS)
5.	Group support activities	Group support activities includes services that aim to improve the quality of life and psychosocial functioning of mental health consumers, through	• Delivered to groups of consumers simultaneously

	Service Types	Definition	Distinguishing Features
		the provision of group-based social, recreational or prevocational activities. In contrast to services in the Mutual support and self-help service type, Group support activities are led by a member of the NGO.	• Primarily engage consumers in one or more social, recreational, prevocational or physical activities • Centre-based or conducted in community environments • Led by an NGO employee or representative *Inclusions:* • Neighbourhood, community and drop-in centres • Structured and unstructured community day programs • Leisure and recreation activities • Psychoeducational programs • Clubhouses *Exclusions:* • Self-help and mutual support activities delivered on a group basis (these are reported under Mutual support and self-help) • Group-based programs focused on assisting clients gain employment, education or vocational training (these are reported under Education, employment and training)
6.	Mutual support and self-help	Mutual support and self-help includes services that provide information and peer support to people with a lived experience of mental illness. People meet to discuss shared experiences, coping strategies and to provide information and referrals (Metropolitan Health and Aged Care Services Division 2003). Self-help groups are usually formed by peers who have come together for mutual	• Group-based services • Comprising individuals with common experience and interest • Led by one or more volunteer/unpaid consumer peers • Provided on a face-to-face basis or through interactive online forums. Please note, while this service type can be conducted though interactive online forums, the online activity is

	Service Types	Definition	Distinguishing Features
		support and to accomplish a specific purpose (Solomon 2004).	not intended to be measured under the Mental health non-government organisation establishments NMDS. *Inclusions:* • Self-help • Warm lines *Exclusions:* • Services that, while delivered by peers, are better categorised in other service types, e.g. peer-led employment-oriented services; personalised support services provided by peer workers • Services where the peer-leader is employed by the NGO (these services will be reported under other service types, e.g. Personalised support or Group support activities) • Mutual support and self-help activities provided for and/or by carers and/or families of people with mental illness (these are reported under Family and carer support) • Online, population-based self-help programs (these are reported under Self-help—online)
7.	Staffed residential services	Staffed residential services are those that provide overnight accommodation in a domestic-style environment, which is staffed for a minimum of 6 hours a day and at least 50 hours per week. Accommodation may be provided on a short, medium or long term basis.	• Deliver services in a setting that provides overnight accommodation to consumers • Domestic-style environment • Consumers are encouraged to take responsibility for their daily living activities • Staff are on-site for a minimum of 6 hours a day and at least 50 hours per week *Inclusions:* • Residential rehabilitation

	Service Types	Definition	Distinguishing Features
			- Residential respite - Crisis residential services - Transitional residential services - Step-up step-down services *Exclusions:* - Facilities that are visited via in-reach services provided by NGO staff but where the residence is not regarded as NGO worker's place of employment - Clinically-staffed residential services
8.	Personalised support—linked to housing	Personalised support services are flexible services tailored to a mental health consumer's individual and changing needs. They include a range of one-on-one activities provided by a support worker directly to mental health consumers in their homes or local communities (Department of Communities 2011). Personalised support—linked to housing includes services that provide personalised psychosocial support that is coordinated with provision of social housing or privately negotiated housing at the point of entry into the program (but not necessarily tied to such indefinitely).	- Primarily delivered on a one-on-one, face-to-face basis - Primarily delivered in the consumer's home or own environment - Provision of personalised support is coordinated with provision of social housing or a privately negotiated housing place at the point of entry into the program (but not necessarily tied to such indefinitely) - Services are tailored to the needs of the individual consumer - May be of varying intensity (e.g. high, medium, low) *Inclusions:* - Coordinated housing and support - Cluster housing programs - Long term supported housing *Exclusions:* - Provision of personalised support initiated independently of any housing arrangements

	Service Types	Definition	Distinguishing Features
			(these are reported under Personalised support—other) • Personalised support services provided to individuals that are targeted only at improving the person's participation in employment, education or vocational training (these are reported under Education, employment and training) • Staffed residential services (these are reported under Staffed residential services)
9.	Personalised support—other	Personalised support services are flexible services tailored to a mental health consumer's individual and changing needs. They include a range of one-on-one activities provided by a support worker directly to mental health consumers in their homes or local communities (Department of Communities 2011). Personalised support—other includes services that provide personalised psychosocial support that is independent of housing arrangements (e.g. provision of social housing or privately negotiated housing) at the point of entry into the program.	• Primarily delivered on a one-on-one, face-to-face basis • Primarily delivered in the consumer's home or own environment • Provision of personalised support is initiated independently of any housing arrangements • Services are tailored to the needs of the individual consumer • May be of varying intensity (e.g. high, medium, low) *Inclusions:* • Outreach support • In-situ individually tailored support *Exclusions:* • Provision of personalised support that is coordinated with provision of social housing or privately negotiated housing at the point of entry into the program (these are reported under Personalised support—linked to housing)

	Service Types	Definition	Distinguishing Features
			- Personalised support services provided to individuals that are targeted only at improving the person's participation in employment, education or vocational training (these are reported under Education, employment and training)
10.	Family and carer support	Family and carer support includes services that provide families and carers of people living with a mental illness support, information, education and skill development opportunities to fulfil their caring role, while maintaining their own health and wellbeing (Mission Australia 2012). These services may be provided in the context of early intervention or ongoing support.	- Explicitly targeted at carers and families - Includes all services focused on family and carer support except staffed residential respite services. Therefore, this includes services that, if they were not targeted at families and carers, would be reported in other service types. *Inclusions:* - Family and carer programs - In-home and/or day respite for carers - Family-focused early intervention services - After hours carers support lines *Exclusions:* - Residential respite services (these are reported under Staffed residential services)
11.	Individual advocacy	Individual advocacy includes services that seek to represent the rights and interests of people with a mental illness, on a one-to-one basis, by addressing instances of discrimination, abuse and neglect. Individual advocates work with people with mental illness on either a short-term or issue-specific basis. Individual advocates:	- One-on-one services - Primary service provided is advocacy - Development of a plan of action - Educate people with a mental illness about their rights *Inclusions:* - Individual advocacy - Legal advocacy *Exclusions:*

	Service Types	Definition	Distinguishing Features
		• work with people with mental illness requiring one-to-one advocacy support • develop a plan of action (sometimes called an individual advocacy plan), in partnership with the person with a mental illness, that maps out clearly defined goals • educate people with mental illness about their rights • work through the individual advocacy plan in partnership with the person with a mental illness (FaHCSIA 2012).	• Systemic advocacy (these are reported under Sector development and representation) • Individual advocacy in the context of delivery of other mental health support services to the consumer
12.	Care coordination	Care coordination services provide a single point of contact (via a Care Facilitator) for people (and their families/carers) with lived experience of mental illness and complex care needs. Care Facilitators will be responsible for ensuring all of the patients' care needs, clinical and non-clinical and as determined by a nationally consistent assessment tool, are being met (Commonwealth of Australia 2012).	• The principal service provided is the coordination of access to a range of services required by the individual • Where other support services are delivered, they are incidental to the principal care coordination role *Inclusions:* • Care coordination *Exclusions:* • Care coordination provided as part of delivering another service type
13.	Service integration infrastructure	Service integration infrastructure includes services that provide infrastructure integration to establish a 'one stop shop' service platform that brings together an appropriate range of mental health-related services, both existing and new, which aim to improve the mental well-being and social participation of people with mental illness.	• Provides the administrative and capital infrastructure to facilitate the co-location of mental health-related services, rather than coordination of care for individual consumers • The focus is the coordination of services, rather than on direct service provision *Inclusions:* • Service coordination

	Service Types	Definition	Distinguishing Features
			Exclusions: • Care coordination for individual consumers (these are reported under Care coordination) • Any type of service delivery to individual consumers
14.	Education, employment and training	Education, employment and training includes services where the principal function is to provide or support people with lived experience of mental illness, in gaining education, employment and/or training.	• The principal purpose is to increase a person's ability to access education, employment and training • Delivered one-on-one or as part of a group • Education and training takes place through a structured program of tuition • The education and training program can result in the attainment of a formal qualification or award (e.g. a Certificate, Diploma or Degree), however, this need not happen in every program *Inclusions:* • Supported education • Employment and vocationally-focused group programs • Individual employment placement and support • Social enterprises *Exclusions:* • Where education is provided as part of delivering another service type
15.	Sector development and representation	Mental health sector development and representation services engage with a wide variety of issues regarding the sustainability and development of the mental health sector. This	• Short, medium and long-term initiatives • Initiatives are intended to benefit the mental health sector, rather than an individual organisation

	Service Types	Definition	Distinguishing Features
		includes information dissemination, advocacy, policy analysis, program development and sector capacity building (Family and Community Services 2012)	• Services are not provided to individual clients but are targeted at developing and/or representing client service delivery organisations operating in the NGO sector *Inclusions:* • Sector-wide advocacy activities • Workforce development • Research and evaluation • Policy activities *Exclusions:* • Individual advocacy (these are reported under Individual advocacy)
16.	Mental health promotion	Mental health promotion includes services that operate on a population level which aim to raise awareness of mental health issues, improve mental health literacy, reduce stigma and discrimination and maximise the population's mental health and well-being. Mental health promotion may include programs targeted to population segments, based on age (e.g. early childhood) or setting (e.g. school or workplace), as well as initiatives to educate the general population. This category also includes community-wide activities that provide information and education designed to enhance community understanding, increase the likelihood of identifying and addressing mental health problems and promote good mental health. These programs may be targeted towards specific at-risk communities or communities affected by disaster or trauma.	• Provision of information and education • Population-based • Typically long-term initiatives *Inclusions:* • Mental health promotion activities • Mental health awareness raising initiatives • Anti-discrimination and stigma reduction activities *Exclusions:* • Mental illness prevention activities (these are reported under Mental illness prevention)

	Service Types	Definition	Distinguishing Features
17.	Mental illness prevention	Mental illness prevention includes services that work to prevent the onset of mental disorders, in order to reduce the incidence and prevalence of mental illness in the community. Mental illness prevention activities are directed at reducing known risk factors and/or preventing people that display early signs of mental illness from developing a diagnosable mental illness. These activities can be either population-wide or targeted at vulnerable segments of the community. In contrast to Mental health promotion**,** which seeks to enhance the population's mental health, Mental illness prevention aims to prevent the development of mental illness.	• Population-based • Vulnerable segments of the community • Typically, long-term activities *Inclusions:* • Mental illness prevention activities *Exclusions:* • Mental health promotion activities (these are reported under Mental health promotion)

Appendix D: Service Types and Metadata Items

Metadata Items & METeOR #	Care coordination	Counselling face-to-face	Counselling, support, information & referral - online	Counselling, support, information & referral - telephone	Education, employment & training	Family & carer support	Group support activities	Individual advocacy	Mental health promotion	Mental illness prevention	Mutual support & self-help	Personalised support - linked to housing	Personalised support - other	Sector development & representation	Self-help online	Service integration infrastructure	Staffed residential services
Source of funding, govt authority mental health identifier, code # 479124	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
ABN, identifier # 429148	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Program name, text # 496474	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Consumer-managed organisation indicator, Yes/No # 480963																	
Not for profit indicator, Yes/No # 373022																	
Number of clients (receiving services), total # 481234	✓	✓		✓	✓	✓	✓	✓			✓	✓	✓			✓	✓
Unique client count accuracy descriptor, code # 479136	✓	✓		✓	✓	✓	✓	✓			✓	✓	✓			✓	✓
Number of service provision telephone calls (direct service activities), total # 443793				✓							✓						
Amount of individual assistance provided, total number (of sessions) # 480817		✓															
Amount of group assistance provided, total number (of group sessions) # 480815		✓															
Amount of individual assistance provided, total hours # 481019		✓															
Amount of group assistance provided, total hours # 481023		✓															
Number of visits to a website (administered by NGO), total # 481033			✓														
Number of online chat sessions conducted with clients, total # 497353			✓														
Number of registered users (online), total # 497046															✓		

Metadata Items & METeOR #	Care coordination	Counselling face-to-face	Counselling, support, information & referral - online	Counselling, support, information & referral - telephone	Education, employment & training	Family & carer support	Group support activities	Individual advocacy	Mental health promotion	Mental illness prevention	Mutual support & self-help	Personalised support - linked to housing	Personalised support - other	Sector development & representation	Self-help online	Service integration infrastructure	Staffed residential services
Number of (client) attendees at events facilitated, total # 481030							✓				✓						
Number of episodes of residential care (completed), total # 534013																	✓
Accrued mental health care days (admitted patient care services) total # 286770																	✓
Number of service contacts to individual clients, total (ie 2 persons involved) # 483060	✓				✓			✓				✓	✓				
Number of contact hours, total (2 or more individuals or groups placed in contact with one another) # 483103	✓				✓			✓				✓	✓				
Number of schools participating in a program, total # 496787									✓								
Mental Health funding provided to NGO from Govt authorities, total Australian currency # 480798	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Full-time equivalent staff (paid), total # 270213	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Hours worked by volunteer/unpaid staff, total hours # 481296	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓			✓
Full-time equivalent staff paid peer workers, average number # 481002	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓
Quality accreditation / certification standard indicator (compliance), code # 435944																	
Quality accreditation / certification standard type mental health, code # 435964																	
Outcome measurement tool indicator, Yes/No/NA # 453490		✓										✓	✓				✓
Address—statistical area, code # 659774	✓	✓			✓	✓		✓	✓	✓		✓	✓	✓		✓	✓

Mental Health Coordinating Council
Building 125, Corner of Church & Glover Streets
Lilyfield NSW 2040

PO Box 668
Rozelle NSW 2039

For further information please contact:

Tel: (02) 9555 8388
E: info@mhcc.org.au