

# MENTAL HEALTH CONSUMER PERCEPTIONS AND EXPERIENCES OF SERVICES (MH-COPES): A FRAMEWORK FOR CULTURAL CHANGE



**BY THE NSW CONSUMER ADVISORY GROUP –MENTAL HEALTH INC. (NSW CAG)**

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**For More Detailed Information on The Research And Outcomes From Stage 2 Of The MH-CoPES Project Refer To Louisa Riste At [Iriste@Nswcag.org.au](mailto:Iriste@Nswcag.org.au) Or Contact NSW Consumer Advisory Group – Mental Health Inc. On 02 9332 0200 Or [Info@Nswcag.Org.Au](mailto:Info@Nswcag.Org.Au).**

## **ABSTRACT**

*Mental Health Consumer Perceptions and Experiences of Services (MH-CoPES): is a tool and framework for consumer participation in quality improvement and to gather consumer perspectives and experiences of services, in public adult mental health services in NSW. This paper gives an overview of Stage 1 Mental Health Consumer Perceptions and Experiences of Services (MH-COPES), before explaining the research, consultations and work completed with AHS in stage 2. Stage 2 finalised the draft Framework for consumer evaluation and the associated Questionnaires ready for full implementation. The framework is an agent for change not only in improving mental health services to meet the needs of the people who use them but also by creating cultural change within the mental health system itself.*

## **INTRODUCTION**

The Mental Health Consumer Perceptions and Experiences of Services (MH-CoPES) project Stage 2, was conducted by the NSW Consumer Advisory Group – Mental Health Inc. (NSW CAG) in partnership with the Mental Health and Drug and Alcohol Office, NSW Health. The project was initiated to develop a framework for consumer participation in service evaluation and quality improvement. Consumer perceptions and experiences of service delivery have been widely recognised in research as well as in state and national policies as crucial to the implementation of effective mental health services (National Mental Health Working Group Information Strategy Committee, 2004; National Health Performance Committee, 2001; NSW Department of Health, 2006a; NSW Government, 2006; Steering Committee for the Review of Government Service Provision, 2009). However in NSW and nationally there is currently no agreed upon mechanism for the gathering of consumer perceptions and experiences of services or consumer participation in mental health service quality improvement and evaluation (Steering Committee for the Review of Government Service Provision, 2009).

### **Background**

Stage 1 of the Mental Health Consumer Perceptions and Experiences of Services (MH-CoPES) Project produced a draft MH-CoPES Framework for Consumer Evaluation of Mental Health Services (the Framework, see Figure 1) and two versions of the Questionnaire. One Questionnaire is for use by consumers of public, adult inpatient mental health services, and the other for use by consumers of public, adult community mental health services. The following principles, underpinning consumer evaluation of mental health services were also produced to guide the development of the Framework:

- Recovery Orientation
- Consumer Participation
- Empowerment
- Accountability
- Continuous Improvement
- Privacy and safety
- Accessible and equitable
- Efficient and Effective
- Service and systems focus

### **METHODS**

Stage 2 of the Mental Health Consumer Perceptions and Experiences of Services (MH-CoPES) Project was conducted in collaboration with MHDAAO and Area Mental Health Services, particularly in Greater Western Area Health Service and Northern Sydney Central Coast Area Health service, where research was conducted in Orange and Ryde in both community and inpatient settings. Research took the form of literature reviews, consultations in the AHS services and a pilot and trial of the Questionnaires and reporting, feedback, action and response to feedback protocols.

## **OVERVIEW OF STAGE 2**

The aim was to build upon the work of Stage 1 to test and finalise the draft Mental Health Consumer Perceptions and Experiences of Services (MH-CoPES) Framework for consumer evaluation of mental health services and the associated Questionnaires ready for full implementation in public, adult mental health services in NSW. Another objective was to obtain an understanding of the cultural and change management issues that need to be addressed to support the full implementation and sustainability of the Mental Health Consumer Perceptions and Experiences of Services (MH-CoPES) statewide. It was acknowledged at the conclusion of Stage 1 that “implementing genuine consumer evaluation processes in mental health services across NSW will essentially involve a further shift in the current culture of services, toward improved consumer and service partnership, and inclusive consumer participation at all levels of services.” (NSW Health, 2006b).

## **THE MH-COPES FRAMEWORK FOR CONSUMER EVALUATION OF MENTAL HEALTH SERVICES**

The Framework was developed to provide a consistent approach for consumers of NSW public, adult community and inpatient mental health services to provide their perceptions and experiences of services and for this feedback to then contribute to directing service improvement initiatives. The Framework is targeted towards generating grouped feedback on the strengths and weaknesses of service quality and delivery, rather than individual issues or concerns.

### **The Framework Consists Of Four Steps:**

#### **Data Collection**

Consumers provide their perceptions and experiences of mental health services using the appropriate Questionnaire, highlighting areas of service strength and areas in need of improvement.

#### **Data Analysis**

Consumers’ combined fixed choice answers and written comments are statistically and thematically analysed to identify areas where mental health services are performing well and areas needing improvement.

#### **Reporting And Feedback**

Reports are produced and distributed to all stakeholders that outline identified areas where services are performing well, and areas needing improvement.

#### **Action And Change**

Results, as presented in reports, are used to produce local, Area and State action plans with the aim of improving the quality of mental health services.

The four steps make up one complete evaluation cycle, with cycles of evaluation to occur repeatedly.

Insert Figure 1 Here

## **RESULTS**

### **The Findings from Stage 2**

The findings from Stage 2 of the project demonstrated that the Mental Health Consumer Perceptions and Experiences of Services (MH-CoPES) Framework (including the MH-CoPES Questionnaires), is a successful and effective mechanism for consumers to participate in quality improvement and to ensure that consumer perspectives and experiences contribute to service change and improvement. A distinctive feature of the MH-CoPES Framework that is absent from the majority of quality improvement frameworks, is its involvement of consumers in each step. This has been one of the key facilitators of the success of the Mental Health Consumer Perceptions and Experiences of Services (MH-CoPES) Project.

The involvement of consumers in each step of the Framework was found in itself to act as a catalyst for cultural change. The ongoing positive interaction between staff and consumers through a legitimised Framework facilitated a change in attitudes towards each other, and a reduction in stigma. The implementation of the Framework in research sites was seen as a highly rewarding process, and has led to the development of further collaborative activities between staff and consumers. The process highlighted for services, the value of consumer participation in services.

### **Protocols for The MH-CoPES Framework**

The experiences of the research as well as the consultations conducted throughout both stages of the MH-CoPES project have resulted in the finalised protocols for the implementation of the MH-CoPES Framework. These are presented in Figure 2.

Insert Figure 2 Here.

### **Frequency of Cycles of The MH-CoPES Framework**

#### **How Often Should The Steps Of The MH-CoPES Framework Occur?**

*Data Collection* occurs as an ongoing process. This means that consumers are offered a Questionnaire upon each discharge from a service and once during each year they are using a service.

*Data Analysis and Reporting and Feedback* occur twice annually

Consultations concluded that receiving reports twice a year is the most effective means for ensuring that the Mental Health Consumer Perceptions and Experiences of Services (MH-CoPES) tool provides information upon which AHS can structure quality improvement projects and monitor the effectiveness of current and previous projects. People consulted viewed this regularity of feedback to be important in keeping MH-CoPES “on the agenda.”

Information on how services are responding to the findings is also to be communicated through the Mental Health Consumer Perceptions and Experiences of Services (MH-CoPES) posters or brochures designed throughout stage 2 of the project. This plays two roles in that it communicates that consumers have been heard in relation to their feedback as well as encouraging their engagement in completing the questionnaire in the future. Posters or brochures are to be displayed in individual mental health services.

*Action and Change* occurs as an ongoing process within current continuous quality improvement systems and processes.

## DISCUSSION

### **Cultural And Change Management Issues That Need To Be Addressed For The Successful Implementation And Sustainability Of Mental Health Consumer Perceptions and Experiences of Services (MH-CoPES)**

To effectively implement and sustain the Mental Health Consumer Perceptions and Experiences of Services (MH-CoPES) Framework in mental health services it is essential to understand the culture of mental health services in NSW, and the organisational change that will be needed to support MH-CoPES, and to develop strategies to facilitate the required change. Three key considerations inform this work:

Implementing the Framework means introducing a new program into mental health services. The literature review and the work conducted in Stage 1 of the project highlight the challenges of introducing and achieving change in any organisation. In particular, resistance to change is commonly faced when introducing any new program to an organisation.

Part of the vision of Mental Health Consumer Perceptions and Experiences of Services (MH-CoPES) is to introduce a mechanism by which consumers' views contribute to service change and quality improvement. Adopting MH-CoPES and implementing the *Action and Change* step in particular will result in changes for everyone within mental health services. It can be anticipated that at times MH-CoPES will challenge practice and culture within mental health services.

Mental Health Consumer Perceptions and Experiences of Services (MH-CoPES) is fundamentally about consumer participation in the quality improvement of mental health services. It is well recognised that the area of consumer participation is not always well understood, and that conflicting values and attitudes are held about consumer participation (Hansen, Hatling, Lidal, & Ruud, 2004; Lloyd & King, 2003).

### **Mental Health Consumer Perceptions and Experiences of Services (MH-CoPES)– A Change Agent**

During Stage 1 of the project it was clearly identified that engagement in the Mental Health Consumer Perceptions and Experiences of Services (MH-CoPES) Framework would likely challenge the dominant culture in mental health services (NSW Health, 2006). The very nature of the Framework involves a mental health service identifying and then acting on feedback to change their practice. However, the research during Stage 2 has demonstrated the effect of MH-CoPES as a change agent beyond this, and through the very process of staff and consumers engaging in working together.

Consultations with staff and consumers at both of the research sites (including Area Executive, senior Area and service staff, consumers, Consumer Workers, service staff, and quality improvement staff) revealed that changes were occurring to how staff and consumers interact. Definitive evidence of why this was occurring was not collected. However those consulted attributed it to engagement in Mental Health Consumer Perceptions and Experiences of Services (MH-CoPES); not just because of responding to and acting on feedback from consumers, but through the engagement in the whole MH-CoPES Framework. The research partners reported:

- that a change in thinking was occurring, which involved “actually listening to consumers’ perspectives” about the services

- the need for cultural change around how staff interact with consumers was highlighted and initiatives considered to enable this change, for example how information is given to consumers
- stigma and stereotyping towards consumers by staff was being reduced as AHS workers were seeing consumers as colleagues – people who are “well and holding down a job”; “capable, dependable, competent, lovely, honest, open, and very funny and enjoyable people”
- while employing consumers in temporary and casual roles proved an initial challenge to the AHS, it was seen to be “paving the way for policy around the employment and payment of consumers for their time and work”
- as a result of the work of the Consumer Project Workers and the positive impact they had not only on return rates to MH-CoPES but also in communicating with consumers (giving hope) during the trial, a directive was given, to hire more Consumer Workers in other sections of the AHS in one research site
- staff in some services began seeking out Consumer Workers to consult and problem solve; previously such consultation and engagement did not occur
- Consumer Workers in the AHS found they were gaining better access to units, including more time, and more easy access to staff and consumers on the units. They reported feeling a change in staff attitudes to their visits
- in one site, Consumer Workers were invited to the staff Christmas party as a result of working more closely with staff through MH-CoPES
- MH-CoPES was a catalyst for other initiatives. In one service further collaborative projects and events were developed and engaged in as a result of the experience of MH-CoPES.

These outcomes demonstrate the power of the Mental Health Consumer Perceptions and Experiences of Services (MH-CoPES) as a change agent. MH-CoPES brings staff and consumers together to work on improving services in a collaborative way, and in many instances during the research, there was clear evidence of people involved realising an alignment of their goals. Frequently when staff reviewed the reports provided, comments of agreement about the issues raised by consumers were made. MH-CoPES therefore assists staff and consumers to find common ground to work together to improve the service. In addition, the reporting of positive feedback about services from consumers through MH-CoPES was found to enhance staff morale and facilitate one way for staff to feel appreciated by consumers.

The repetitive cycle of the Mental Health Consumer Perceptions and Experiences of Services (MH-CoPES) framework will result in improvements to services that both staff and consumers will benefit from. As consumers experience these improvements, it is anticipated that, over time, this will be reflected in the way consumers respond in the Questionnaire, and thus provide staff with further positive feedback that the process of change is leading to better services. The whole process of MH-CoPES will therefore ignite cultural change through shifting services to better meet the needs of consumers, as identified by consumers.

The implementation of the Mental Health Consumer Perceptions and Experiences of Services (MH-CoPES), a Framework developed by and for consumers and a Framework that engages consumers in all aspects of service evaluation, throughout public, adult mental health services in NSW makes a clear statement about the value of consumer participation in practice. The Framework provides one mechanism for consumer participation in service evaluation, development and monitoring. Through placing consumers in a position of being informants and as people with valuable knowledge, the MH-CoPES Framework assists in altering the power balance between services, staff and consumers and works to change how consumers are perceived.

“It’s empowering consumers to make a change for consumers” (Consumer Worker)

“The Consumer Project Workers are the ones who have really made it work” (Senior AHS staff, throughout the Data Collection)

“It normalised having consumers involved in things” (Senior AHS Staff)

“The Consumer Project Workers became seen as very much a benefit [by staff]” (Senior AHS staff)

“A round of applause to MH-CoPES for letting us have our say” (Consumer attending an MH-CoPES consultation)

“The Framework provided a catalyst for cultural change” (Senior AHS staff)

“Paving the way for us [Consumer Workers] only needs to be done one” (Consumer Worker)

## **CONCLUSION**

As evidenced in the various state plans (the *NSW State Plan*, the *NSW State Health Plan* and the *NSW State Plan for Mental Health*, NSW Health, 2006a,b, 2007), NSW has been advocating for greater consumer participation in all aspects of service delivery. Mental Health Consumer Perceptions and Experiences of Services (MH-CoPES) provides a Framework for realising strong consumer participation in practice, from evaluation of services right through to informing and implementing service improvements. It thus provides a mechanism for consumer participation in service evaluation, development and planning, and policy development.

The Mental Health Consumer Perceptions and Experiences of Services (MH-CoPES) Framework provides the necessary strategies and structures for implementing consumer evaluation of mental health services to ensure service improvements are derived from consumer feedback. Further, the work of Stage 1 and 2 of the MH-CoPES project has highlighted that only a statewide program such as MH-CoPES can drive service change at three levels: local services, Area Health Service and the state.

The Mental Health Consumer Perceptions and Experiences of Services (MH-CoPES) Framework has been developed over 6 years, with extensive consultation with consumers, carers, service providers, NSW Health and other stakeholders, and testing through the research in metropolitan and rural services, as well as across services in NSW through the statewide introduction. It has been informed by the nine principles underpinning MH-CoPES. The experiences of the research as well as the consultations conducted throughout both stages of the MH-CoPES project have resulted in a set of protocols that form a

comprehensive strategy for the effective implementation of MH-CoPES throughout public, adult inpatient and community mental health services throughout NSW.

Mental Health Consumer Perceptions and Experiences of Services (MH-CoPES) is designed to bring staff and consumers together to work towards improving services in a collaborative way. By doing this the Framework also acts as a powerful change agent, breaking down the traditionally held barriers between consumers and service staff and enhancing awareness around the value of consumer participation in mental health services. It was found during the research in Stage 2 that MH-CoPES appeared to act as a catalyst for cultural change, not only in improving mental health services to meet the needs of the people who use them but also creating cultural change within the mental health system itself.

## REFERENCE LIST

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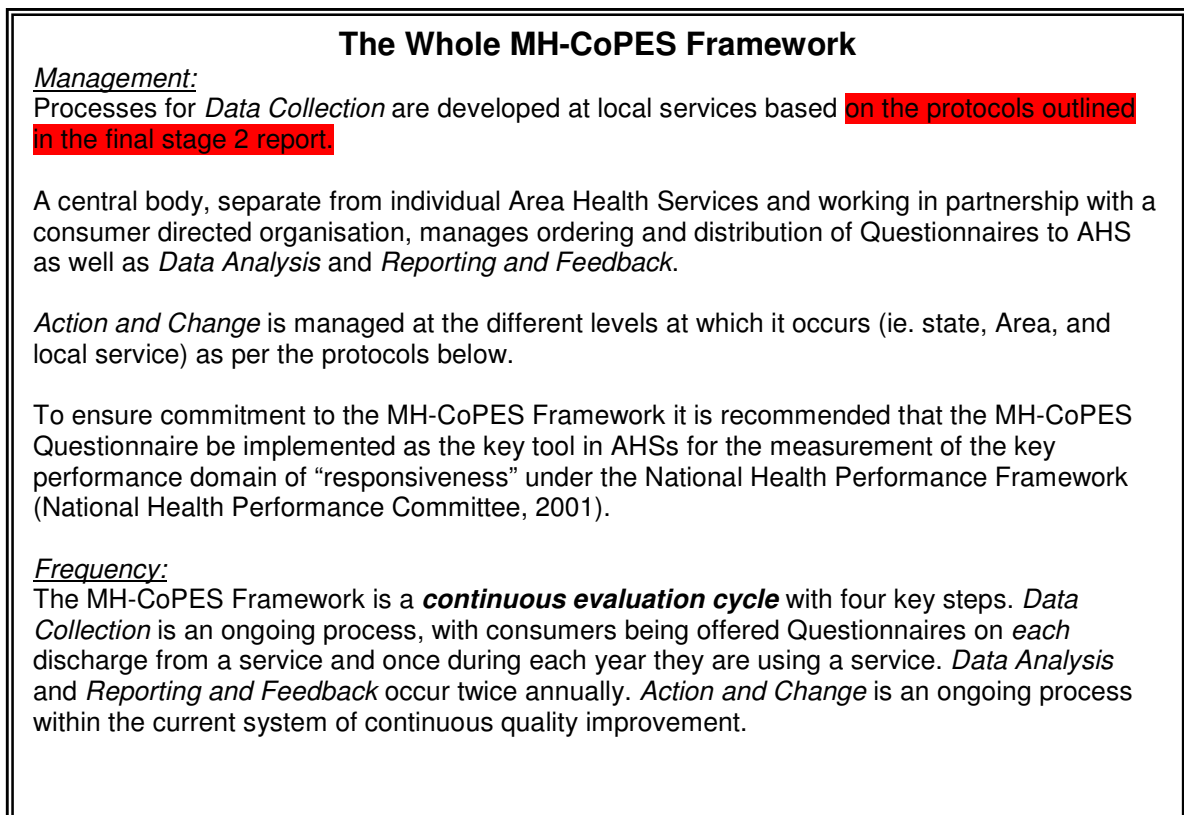
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Figure 1. The MH-CoPES Framework



Figure 2. Protocols for the MH-CoPES Framework



## Data Collection

Tool for Data Collection: The MH-CoPES Questionnaires are adopted as the primary mechanism for collecting consumers' views of services

Support to complete the Questionnaire: Consumer Workers are available to provide support to people who need it to complete the Questionnaire with all distribution methods used

Consumers may seek assistance from family, carers or friends as stated on the Questionnaire

Staff may assist consumers to access support, however, do not offer support to complete the Questionnaire themselves

### Distribution method:

Where possible, Consumer Workers distribute the Questionnaire, as they are then immediately available to provide assistance to complete the Questionnaire

Administrative and clinical staff (including case workers) may distribute Questionnaires

In community services, Questionnaires may be mailed to consumers where an adequate, up to date system to do this is available

Distribution may occur individually or in a group setting

Questionnaires may be included in discharge packs

### When to distribute the Questionnaire:

Acute inpatient Services: upon discharge

Long term inpatient services: once annually while using service and upon discharge

Community services: once annually while using service and upon discharge

Return methods: All Questionnaires include a reply paid envelope, and all services have a MH-CoPES Questionnaire return box with a combination lock installed.

Questionnaires are returned unopened to the organisation undertaking data analysis

## Data Analysis

### Analysing the fixed choice section of the Questionnaire:

Two methods of analysing the fixed choice data are adopted:

- Method 1 uses the mean score for each question to assign it to one of three categories:
  - Strengths
  - Needing some improvement
  - Needing lots of improvement

This allows for comparison of results with other services and the Area average

- Method 2 ranks the service's mean scores for each question with each other to allow for the individual service's strengths and weaknesses to be identified

### Analysing the written comments section of the Questionnaire:

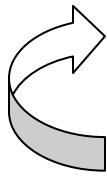
The data from the three written comments questions in the MH-CoPES Questionnaire be analysed together and presented as one set of findings

Written comments data analysed using Ethnographic Content Analysis to produce results for local level reporting

The categories that emerge during Ethnographic Content Analysis are further refined using an inductive thematic approach for reporting at AHS and state level

A maximum of 10 final topics or themes are included in reports

**Consumers are to be involved in the analysis of written comments**



## Action and Change

MH-CoPES is incorporated into state, Area and local service quality improvement processes and systems

Areas identified in MH-CoPES reports as most in need of improvement are key aspects guiding quality improvement initiatives at the state, Area and local levels

*Action and Change* is an ongoing process informed by each MH-CoPES report

NSW Health, AHS and local services have processes in place to ensure consumers are involved in state, Area and local quality improvement processes, including consumers having an opportunity to articulate their views on how they see changes as needing to happen, and consumer representation on quality committees

Service staff are involved in discussions around how improvements can happen within their service

Feedback mechanisms are developed for informing consumers and staff at the state, Area and local level about the *Action and Change* initiatives that have resulted from MH-CoPES

There are local MH-CoPES champions who can drive MH-CoPES and have clear lines of responsibility and management for *Action and Change* at state, Area and local service levels

Culture of valuing and accepting the perspectives of consumers, the value of consumer participation in service improvement, and the culture of continuous quality improvement are fostered and promoted by executive and management at state, Area and local service levels



## Reporting and Feedback

### Processes:

Reporting occurs twice yearly

Results are made publicly available and accessible to current and former consumers

Results are made available to the Official Visitors, the NSW Consumer Advisory Group – Mental Health Inc, and local consumer networks and groups

### The Reports:

A range of mechanisms is used to report back to consumers including posters, newsletters, and discussion of findings at consumer groups.

Reports are produced for:

- Individual services/units
- Area Health Services
- NSW Health

Raw de-identified data is sent to each AHS so they may conduct further analysis if required.

Raw de-identified data is NOT to be sent to individual service units; this means that quotes from people's comments in the written comments section of the Questionnaire are not be included in reports.

