A statewide approach to measuring and responding to consumer perceptions and experiences of adult mental health services

A report on stage one of the development of the MH-CoPES framework and questionnaires

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Foreword

There is a wealth of evidence available to demonstrate that consumer input into evaluation of mental health services can improve the quality and responsiveness of services. As well, consumer evaluation of services is considered an essential component of comprehensive strategic planning and development.

The Mental Health Consumer Perceptions and Experiences of Services (MH-CoPES) project is one of a number of initiatives funded by the NSW Department of Health through the Mental Health Information Development Agreement, a funding agreement with the Australian Government. The first stage (Stage 1) of the MH-CoPES project was conducted over two years, between January 2004 and December 2005. It provides crucial information about the challenges of developing mechanisms for consumer evaluation of mental health services, and indicates a guiding vision for continued development of consumer evaluation of mental health services in NSW.

In 2001, consumers attending the Mental Health Outcomes Assessment Training/Tools (MHOAT) Consumer Consultative Committee identified that consumers' views about service quality and delivery should be understood, and responded to, as part of service quality improvement. The proposal for the MH-CoPES project emerged, with a firm recommendation that the project be conducted by and with consumers.

The project has been conducted through a partnership between the Centre for Mental Health, NSW Department of Health and the NSW Consumer Advisory Group – Mental Health Inc (NSW CAG). MH-CoPES demonstrates a commitment to partnership with consumers of mental health services, and to a genuine vision for consumer participation in NSW mental health services.

Stage 1 has seen a robust partnership process between consumers and service staff. The project's Technical Working Group consisted of consumers and service providers. Consultations were held across NSW attended by over 230 consumers, service providers and other key stakeholders, who contributed to identifying the issues and challenges, and appropriate approaches to consumer evaluation of mental health services in NSW.

Stage 1 of MH-CoPES has produced:

a. The draft MH-CoPES Framework for Consumer Evaluation of Mental Health Services; and

b. The draft MH-CoPES Questionnaire.

These will be trialed and further developed during Stage 2.

MH-CoPES is one part of a complete quality improvement vision for NSW Health, Mental Health programs. The Framework and tools presented in this report were developed to stand alongside other quality activities occurring in Area Health Service, Mental Health programs. National interest has also been shown in including MH-CoPES as an indicator within the National Performance Framework.

The recommendations and outcomes from this project provide clear directions for further development of NSW Mental Health Services' approach to hearing and responding to consumers' perceptions and experiences of services. These directions will be realised through Stage 2 of the MH-CoPES project, which has been funded by the NSW Department of Health to continue the work outlined in this report.

David McGrath

Director, CMH

Anna Saminsky

Chairperson of NSW CAG

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Robert Cairns, Consumer Consultant, SWAHS

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Martyn Wilson, Manager, Community Mental Health, St Vincent's Mental Health Services, SES/IAHS (former position)

Gavin Stewart, Project Director, Research and Evaluation, CMH

And to the project's Management Team:

Robyn Murray, Manager, Clinical Partnerships, CMH

Douglas Holmes, Executive Officer, NSW CAG.

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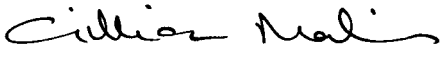

Dr Gillian Malins PhD

Project Officer

Executive summary

What this report is all about

This report is all about:

- people who use mental health services (consumers) in NSW giving their feedback to services, and
- services and consumers working together to create better mental health services.

Consumer perceptions and experiences of service delivery have been widely recognised as crucial to understanding service quality. This is the final report and recommendations from the Mental Health Consumer Perception and Experiences of Services (MH-CoPES) project, Stage 1. This project was established to better understand how consumer perceptions and experiences of mental health services (MHS) can contribute to improving NSW services.

The MH-CoPES project, Stage 1, was conducted by the NSW Consumer Advisory Group - Mental Health Inc (NSW CAG), in partnership with the Centre for Mental Health, NSW Department of Health. The Technical Working Group (TWG) was established, consisting of consumers and service providers, to oversee the project in January 2004.

This report describes Stage 1 of the project, the development of the MH-CoPES Framework for Consumer Evaluation of Mental Health Services (The Framework), and the draft questionnaires or tools to assist in the process of consumer evaluation of their services. The report details recommendations developed in Stage 1 that will form the basis for trialling the Framework and the tools in Stage 2.

The MH-CoPES project, Stage 1

The primary aim of Stage 1 of MH-CoPES was to scope the views and requirements of key stakeholders on development of a Framework for Consumer Evaluation of MHS for NSW public mental health services, adult programs, to include consumers' views of the quality and delivery of the mental health services they receive in continuous service improvement. The Framework and tools were envisaged for systemic use by AHS mental health services, consumers, and the NSW Department of Health.

The recommendations and outcomes from Stage 1 of MH-CoPES provide clear directions for further development of NSW Mental Health Services' approaches to hearing and responding to consumers' perceptions and experiences of services. Stage 2 of MH-CoPES will analyse the processes proposed in greater depth to understand the funding implications, alternatives, and viability of the proposed Framework. Recommendations made to the Department of Health during Stage 2 will offer clear advice on options for state wide implementation. Future work is required also to consider other age groups and cultural issues.

MH-CoPES has firmly established consumer evaluation of MHS as a continuous quality improvement initiative. Information collected needs to be used to improve services for everyone. Stage 1 of MH-CoPES focused on ensuring that a method not just to hear (or measure) consumers' views about service delivery was developed as an outcome of the project, but that the framework necessary to enable services and consumers to work together based on the feedback was also developed.

MH-CoPES is one part of a complete quality improvement vision for NSW Health, Mental Health programs. MH-CoPES will form part of the cycle of information processing that occurs within NSW MHS, and existing information data collection cycles need to underpin this. The Framework and tools presented in this report were developed to stand alongside other quality activities occurring in AHS mental health programs. The MH-CoPES evaluation process will add a stronger consumer perspective to considerations of quality service delivery, and to the planning and development of better services for the future.

In this report, the products from Stage 1 of the project are presented. These include:

1. the MH-CoPES Framework for Consumer Evaluation of Mental Health Services, and
2. the tools developed to assist this process. In Stage 1, two versions of the MH-CoPES Questionnaire were

"systems of accountability must be collaborative and include a wide variety of stakeholders in the production and management of health information" [1]

developed; one for use by consumers of inpatient mental health services, and the other for use by consumers of community mental health services.

Principles of MH-CoPES consumer evaulation

Nine principles were identified which underpin the work and products presented here. The principles demonstrate a commitment to using consumers' feedback to improve mental health service delivery. The nine principles are:

Recovery orientation:

A recovery orientation to service provision means that at a systems level mental health services are to be guided by consumers' experiences and views of what works and what does not. Consumer evaluation of services is a central feature of a recovery orientation.

Consumer participation:

Consumer evaluation of mental health services is an enactment of genuine consumer participation, most particularly at service and systems levels.

Empowerment:

Consumer evaluation of mental health services is fundamentally informed by, and directed towards creating opportunities for consumer empowerment.

Accountability:

Services are accountable to consumers, families and carers, staff, funding bodies, and the NSW community.

Continuous improvement:

Services should be striving to develop and advance their service delivery as a core part of their work. Continuous improvement is one of the quality indicators of NSW Health.

Privacy and safety:

Evaluation of mental health services should be an activity that consumers and staff engage in, knowing their individual privacy will be maintained without fear of adverse repercussions.

Accessible and equitable:

Evaluation processes should be freely available to everyone wishing to become involved.

Efficient and effective:

The process of consumer evaluation should be easy to engage in, without creating unnecessary extra burden for consumers, staff or services. The process should also be effective, in that it guides service change on the ground.

Service and systems focus:

The primary focus of consumer evaluation of services is to identify problems within the system, and at service levels. It is not aimed at identifying problems at individual levels, which is the focus of other quality processes in services.

Developing the MH-CoPES Evaluation Framework and Questionnaires

To develop the MH-CoPES Framework for Consumer Evaluation and the Questionnaire, the TWG:

- reviewed national and international literature relating to performance and quality frameworks, satisfaction surveys, consumers' perceptions and experiences of mental health services, recovery and well-being, and changing practice and culture in the mental health services;
- reviewed consumer evaluation initiatives in NSW mental health services, by conducting a survey within Area mental health and non-government services;
- identified and reviewed existing frameworks and tools for consumer evaluation of mental health services; and
- consulted with key stakeholders around NSW about consumer evaluation of mental health services.

The MH-CoPES Framework for Consumer Evaluation of Mental Health Services

The MH-CoPES Framework for Consumer Evaluation consists of four phases, in keeping with the principles of continuous improvement. The purpose of the Framework is to guide a consistent approach to consumer participation in quality improvement across NSW mental

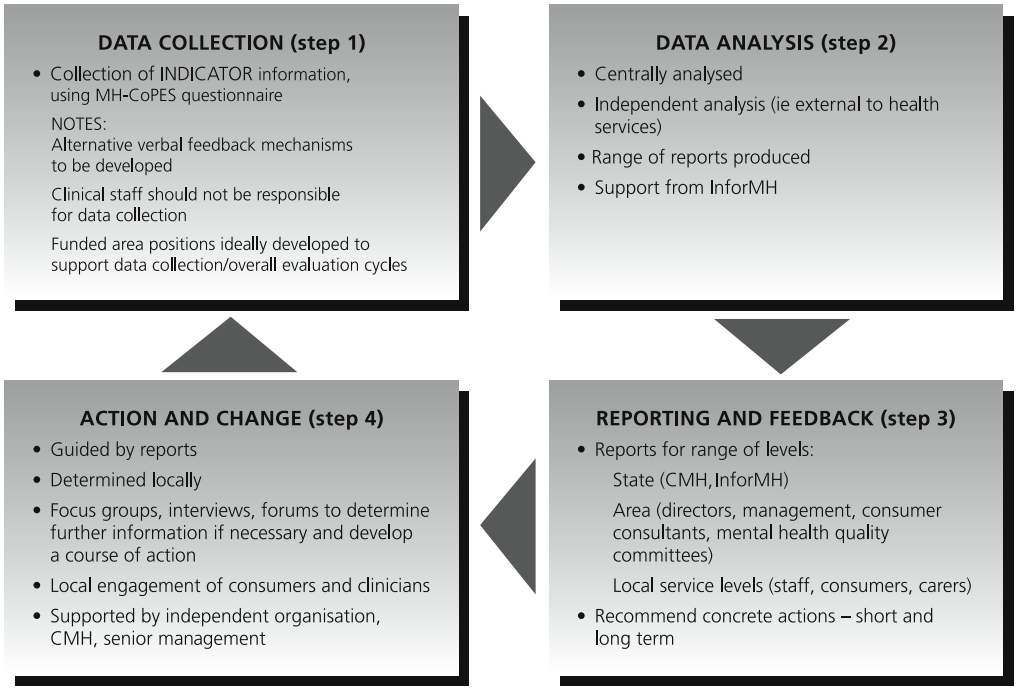

Figure 2.

A four-step model of MH-CoPES consumer evaluation of mental health services

health services. The Framework will guide the steps consumers and services need to take to ensure consumers' views of service quality and delivery are heard by services, and used to direct service improvement (see figure 2).

Two versions of a Questionnaire, one for use by people in current/recent contact with inpatient mental health services, and the other for people in current contact with community mental health services have been developed as part of Stage 1 of the project. The differences reflect the different service settings.

The questionnaires were developed to be one option that consumers and services could utilise to assist in the process of consumer evaluation of mental health services. They were developed to:

be used during the data collection phase of the MH-CoPES evaluation;

assist consumers in providing feedback to the mental heath services they use; and

assist mental health services to hear consumers' feedback.

Recommendations

Based on the findings of the MH-CoPES project, Stage 1, the following recommendations are made for developing opportunities for consumer evaluation of mental health services in NSW. Stage 2 of MH-CoPES will continue the work commenced in Stage 1 by considering issues of resource and funding implications, burden on clinicians and the viability of the options proposed by stakeholders in Stage 1.

1. Adopt the principles of consumer evaluation to guide all further development of the MH-CoPES Framework for Consumer Evaluation of Mental Health Services, and associated Questionnaire (see section 3 of this report for discussion of the principles and section 4 for MH-CoPES Framework);

2. Trial the MH-CoPES Framework for Consumer Evaluation of Mental Health Services within AHS mental health services, to continue development of a robust state wide framework, and ensure consumer participation in evaluating mental health services is a routine part of

quality improvement and service planning as the *National Standards for Mental Health Services* require;

3. Clarify the role and place of consumer evaluation of mental health services through the MH-CoPES Framework for Consumer Evaluation in service improvement, and continue to build a united vision and partnership approach between the Centre for Mental Health, AHS mental health services and consumers, plus other stakeholders, for consumer evaluation through MH-CoPES;

4. Pilot the Questionnaire developed at Stage 1 to establish its validity, reliability and associated properties, and develop the Questionnaire more fully in context;

5. Develop and trial alternative methods of data collection and feedback tools, particularly verbal options, for consumers to give their feedback, which will provide comparable information in parallel to the questionnaire method developed in Stage 1;

6. Develop and trial differing modes of questionnaire administration;

7. Support the ongoing development of the MH-CoPES Framework for Consumer Evaluation through access to the expertise of InforMH to support establishment of process management and data analysis procedures;

8. Work with AHS mental health services and other key stakeholders across NSW to develop and trial reporting and feedback protocols for MH-CoPES data, collected through implementing the MH-CoPES Framework for Consumer Evaluation;

9. Work with AHS mental health services and other key stakeholders across NSW to develop and trial action and response protocols for MH-CoPES evaluation; and

10. Assess the training needs within mental health services relating to MH-CoPES consumer evaluation and develop training protocols to support implementation of the MH-CoPES Framework for Consumer Evaluation.

Introduction

"clearly, consumer perceptions about treatment efficacy and satisfaction with the type of treatment received, as well as the way it is delivered, determine which treatments are sought or complied with and which outcomes are valued." [1]

The importance of consumers' perceptions and experiences of mental health services as an indicator of service quality has been widely recognised.[1, 2] Consumers' views of service effectiveness have been clearly demonstrated as frequently different from those of clinicians, management, policy makers and familes.[3, 4, 5, 6] Additionally, it is evident that outcomes are not simply a direct result of services received, but rather, the result of multiple factors. Consumers' perceptions and experiences of the services they receive are central to the outcomes that are achieved.[7, 8, 9] The growing body of literature focusing on recovery from mental illness also establishes the importance, from consumer perspectives, of things frequently not considered or prioritised by health services, as affecting health outcomes. It is clear from this body of literature that recovery-oriented mental health services aim to achieve some different outcomes such as securing meaningful work or addressing spiritual issues, and importantly, also go about achieving these outcomes in different ways.[10, 11, 12, 13]

Consumer evaluation of Mental Health services is about real participation in service improvement…it is about creating services that better meet consumers' needs.

Consumer participation in evaluation of mental health services in Australia is endorsed by national and state policies, such as the *National Mental Health Plan 2003–2008*, and the *Framework for Managing the Quality of Health Services in NSW* [14, 15, 16, 17] As well, involvement of communities in determining health priorities and allocation of health resources has been identified by the World Health Organisation (WHO) as an essential element in improving peoples' health.[18] However, enactment of genuine participation is still limited, posing a serious challenge to the effectiveness of mental health service delivery.[19]

While participation means a range of things to consumers, a central, collective understanding is that participation has an "end goal of creating services that better meet [consumers'] needs."[20] (p. 25).

Consumers' views of services have traditionally been sought by mental health services through satisfaction surveys. These surveys, however, are widely recognised as being severely limited, not least because they often do not reflect issues considered to be important by consumers. Additionally, without being embedded within comprehensive frameworks for continuous improvement, satisfaction surveys alone do not constitute meaningful participation in service evaluation.[3]

The MH-CoPES project formally commenced in January 2004, conducted by the NSW CAG in partnership with the Centre for Mental Health, NSW Department of Health. The MH-CoPES project was established to identify a framework for consumer evaluation of mental health services, to use across NSW Health, adult mental health programs. The purpose of the MH-CoPES initiative is for consumers' feedback about their experiences of using a mental health service to become a central component of the quality improvement processes of mental health services.

1.1 **Background**

The project has its origin in the Mental Health Outcomes Assessment Training/Tools (MHOAT) Consumer Consultative Committee's (MHOAT CCC) first few

Table 1.

Criteria for technical working group members

Stakeholders Criteria	NSW CAG	Rural consumer	Urban consumer	Health service provider
1. Be a consumer	•	•	•	
2. Be a service user	•	•	•	
3. Have an established network to feedback to (either in terms of consumer participation, advocacy or support).	•	•	•	•
4. Knowledge of MH-OAT, National Standards and Policy and NSW Mental Health Policy	•	•	•	•
5. An understanding of surveys or reviews of health services	•	•	•	•

meetings, held in 2001. The MHOAT CCC was convened by the Centre for Mental Health, NSW Department of Health, as a forum for consumers to discuss issues relating to the introduction of routine consumer outcomes measures in NSW mental health services. The MHOAT CCC took the view that, while clinical outcomes were important, other aspects of services also needed to be assessed. In particular, this committee was concerned with ensuring that consumer perceptions and experiences of service quality and delivery be heard and responded to, as part of routine practice. From the initial discussions a proposal for the MH-CoPES project was developed to address this gap. The MHOAT CCC also proposed that the project should be largely managed by consumers of mental health services.

1.1.1 The MH-CoPES Technical Working Group

During 2003, a Technical Working Group (TWG) for the MH-CoPES project was recruited via state wide advertisements. Applicants to the TWG were required to meet the criteria outlined in Table 1.

In addition to the members listed in Table 1, a methodological consultant and nominee of the Centre for Mental Health completed the TWG.

The terms of reference for the MH-CoPES Technical Working Group were to:

- approve the project proposal;
- approve the proposed budget allocation;
- advise the Project Officer;
- inquire into and make recommendations to the Centre for Mental Health on appropriate processes and tools for consumer perceptions and experience of services to be heard and responded to as part of routine practice;
- plan, manage and report on the results of the project on a quarterly basis; and
- recommend the acceptance of the report to the Centre for Mental Health on completion of the project.

Eight consumers, three mental heath service providers, a methodological consultant and a representative from the Centre for Mental Health were recruited to the TWG. Members were paid for their work on the project, funded either through support from their AHS as part of their existing roles, or through allocated project funds.[21] With guidance from NSW CAG, the TWG spent their first meetings establishing the group process and determining the job description for a Project Officer. The Project Officer commenced work in January 2004, and the team then met on a regular basis over 18 months. The project's Management Team also met regularly, and there were regular updates to the Centre for Mental Health and Area Mental Health Directors.

A Framework*: a guide to the overall structure, parts and processes involved in consumer evaluation of mental health services.*

Tools: *instruments used to do a particuar job. In the context of consumer evaluation of mental health services, useful tools could include questionnaires, interviews, databases and methods of data analysis. In Stage 1, the focus was on developing a questionnaire.*

Table 2.

MH-CoPES vision

To develop a formal mechanism for consumers' voices to be recognised in practice and recognised as essential to guiding services;

To develop tools and processes which assist services to become more responsive and accountable to consumers;

To augment existing quality processes in NSW mental health services by developing a mechanism whereby consumers' views contribute to continuous service improvement; and

To establish a formal mechanism that builds dialogue and partnership within NSW mental health services around issues that are important to consumers.

1.1.2 Aim and objectives

The aim of MH-CoPES is to provide a genuine opportunity for consumers to express their perceptions and experiences of services, and for these perspectives to direct service change and development.

The vision for the MH-CoPES project is summarised in Table 2.

The primary aim of Stage 1 of MH-CoPES was to scope the views and requirements of key stakeholders on development of a Framework for NSW public mental health services, adult programs to include consumers' views of the quality and delivery of the mental health services they receive in continuous service improvement. The objectives of the project were to:

- develop a framework for MH-CoPES consumer evaluation of mental health services in NSW AHS, mental health services; and
- identify or develop tools to assist in the conduct of consumer evaluation, consistent with the Framework developed.

The Framework and tools were envisaged for systemic use by AHS mental health services, consumers and the NSW Department of Health.

1.1.3 **Complementing existing quality processes in NSW mental health services**

Essentially, if implemented, the Framework produced by the MH-CoPES project will complement existing quality processes within NSW Health, contributing a further mechanism by which service quality can be monitored and managed. The MH-CoPES approach will explicitly contribute to existing quality processes by providing a means for consumers' views of service delivery and quality to be heard, and impact on the way services operate.

While for consumers, outcomes and experiences of services are often closely related,[22] the focus of MH-CoPES was specifically on consumer perceptions of the services they use. In a comprehensive review of the area, Slade[23] found seven categories of outcome. Slade named one of these seven domains "services," which he states includes: "both positive and negative aspects of receiving mental health care." (p. 748). He suggests that the "services" domain only came into prominence in the research and literature in the mid-1990s.

In line with Slade,[23] the TWG took the position that consumer perceptions and experiences of the services they use should be considered as an issue distinct from other outcome domains. Importantly, consumers' evaluations of services should be seen as reflective of the state and performance of the service, rather than as an indicator of the consumers' mental health or recovery, as other outcome domains are. Others in the field support this view of consumer evaluation of services.[24, 25]

The *Framework for Managing the Quality in Health Services in NSW*[17] has a number of consumer participation indicators that MH-CoPES directly addresses for mental health services. These include:

- demonstrated evidence of consumer involvement in assessment of feedback about service delivery (Phase 2 indicator);
- the service conducts regular proactive review of potential areas of complaint (Phase 2 indicator);
- there are systems in place to facilitate wide involvement of consumers, community members and groups in the health system (Phase 2 indicator);
- percentage of patients who perceive that they have received sufficient and appropriate information regarding their condition or treatment (Phase 2 indicator);
- evidence of effective strategies for consulting and involving disadvantaged groups in the community (Phase 3 indicator); and
- implementation of an effective patient satisfaction measure (Phase 3 indicator).

Information obtained through implementing the MH-CoPES Framework will complement the information collected through existing systems, including the:

- MHOAT, which focuses on clinical outcomes measures. Most of the assessment tools used in NSW are clinician rated, with the Kessler 10 (K-10) being a consumer rated measure, which provides information about symptoms and can be used to track changes in clinical outcomes;
- Sentinel Events Review Committee Findings;
- Official Visitors Program;
- Local AHS, mental health service Quality Review Committees; and
- Complaints and comments systems.

In NSW, InforMH is the service that centrally manages collection and analysis of mental health service information for NSW Health. The Framework developed by the MH-CoPES project, once implemented, will build a stronger consumer perspective into the overarching quality processes. The information gained through MH-CoPES will inform other initiatives.

While the MH-CoPES Framework for Consumer Evaluation will not stand alone, the TWG determined that it was important to develop a framework based on quality

improvement cycles, to:

1. ensure not just collection but also use of consumers' feedback about experiences of service quality and delivery; and

2. ensure opportunities for genuine participation and partnership between consumers and services.

Recognition of the importance of using consumer feedback in service improvement is not new: the view that consumer participation should be intrinsically linked to quality assurance activity was integral to a model of consumer participation developed by Wadsworth and Epstein[26] in 1996 and further elaborated by Epstein and Shaw[27] in 1997.

1.1.4 **Scope of the project**

Primarily, Stage 1 was to collate the bodies of literature relevant to consumer participation in evaluating MHS, and feedback from consultations with consumers, service providers and other key stakeholders in NSW about this issue to propose a broad Framework for further development. Stage 1 did not encompass a full exploration of risks, resource and funding implications, or the additional burden on services or staff. This analysis will be a key focus for Stage 2.

MH-CoPES Consumer Evaluation will contribute to existing quality processes in NSW by providing a way for consumers' views of service quality and delivery to impact on the way services operate.

The experiences and perceptions of all people who interact with mental health services are important in building a greater understanding of quality services. The MH-CoPES project, Stage 1, specifically aimed to develop an approach to facilitate feedback about service quality and delivery, and participation in quality improvement, by adults who are current or recent consumers of public mental health services in NSW.

The term consumer refers specifically to: "individuals who use or are potential users of [mental] health services" [28] (p. 77). The term consumer has been used elsewhere at times to refer to carers and family members of the person who has experienced mental/emotional distress,[28] however, in this report, carers and family members will be referred to separately. The scope of MH-CoPES Stage 1 does not extend to the views of carers and family members, although the importance of their views in contributing to a greater understanding of quality mental health services is recognised. A separate project is envisioned at some stage to complement MH-CoPES, specifically targeted at facilitating evaluation of services by family and carers.

It was highlighted during consultation forums that the views of those people who:

a) choose not to use public mental health services either through their choice to use private services or to refuse services; and/or

b) may currently be in need of mental health services, but for a number of reasons (eg: homelessness) may not be receiving services

are also essential for services to hear and acknowledge, in order to better understand and improve the public system. However, this is beyond the scope of Stage 1 of the MH-CoPES project, and remains a challenge for NSW Health to consider.

While this report and recommendations may prove useful to the non-government and private sectors, the scope of MH-CoPES Stage 1 was specifically to address the challenges within public services provided by NSW Health. While MH-CoPES may inform the solutions for other services, they are also likely to face different challenges and require unique solutions. Within the non-government sector, the NGO Development Strategy: Mental Health initiative, being conducted by the Mental Health Coordinating Council in partnership with NSW Health, is addressing parallel issues to MH-CoPES, as well as considering outcomes measurement.

Other projects are required to develop approaches to hearing and understanding other key stakeholders perspectives, importantly carers' and staff. The MH-CoPES Framework for Consumer Evaluation will stand alongside those developed by future projects. Importantly, the whole of lifespan needs to be addressed, and future efforts will need to focus on issues of consumer evaluation specific to children, adolescents, as well as older consumers.

Particular attention will also be required to address the needs of people from culturally and linguistically diverse backgrounds, and Aboriginal and Torres Straight Islander consumers. The applicability of the recommendations carried in this report will require robust critique and discussion amongst people from these groups to develop appropriate modifications and alternatives for people from diverse backgrounds.

Finally, an important parameter of the MH-CoPES project, and its resultant products, is to facilitate a population level process. This means that the Framework and tools have not been developed to facilitate resolution of individual issues and concerns. Data will be aggregated, and local services will receive group information, providing an indication of what consumers judge to be the strengths and weakness in service quality and delivery within specific areas.

1.2 **Overview of the report**

This is the final report and recommendations from the MH-CoPES TWG, at the completion of Stage 1 of the project.

In section 2, the process of conducting the MH-CoPES project is described. Firstly, the key activities outlined in the original project brief are presented, and following these, the work conducted to develop the MH-CoPES Framework for Consumer Evaluation of Mental Health Services and the Questionnaire is described. This work involved reviewing national and international literature, identifying processes and tools already produced to guide consumer evaluation of mental health services, and a number of consultations with key stakeholders around NSW. Area Health Service amalgamations occurred during the consultation phase of the project, with 17 Areas merging into eight. Area Health Services listed within this report are the original 17 Areas in place when the project commenced.

In the third section of the report, the nine principles the TWG identified as underpinning consumer evaluation of mental health services and MH-CoPES are presented. These principles have guided the decisions made by the TWG in developing the Framework and Questionnaires.

The MH-CoPES Framework for Consumer Evaluation of Mental Health Services is presented in section 4. The basis of the evaluation cycle is described, followed by a detailed discussion of the four phases of:

data collection;

data analysis;

reporting and feedback; and

action and change.

Following from this, the MH-CoPES Questionnaire is presented. Two versions of the Questionnaire have been developed: one for use by people who have recently used inpatient mental health facilities, and one for use by people who have current contact with a community mental health service.

In section 6, the recommendations resulting from the work conducted in Stage 1 of MH-CoPES are presented. Ten recommendations are made followed by the presentation of a number of key issues and strategies identified as requiring consideration during the future stages of MH-CoPES.

In the final section of this report the conclusions and a discussion regarding the possible future directions for the MH-CoPES project, Stage 2, are presented.

SECTION 2

The project process

2.1 Conducting the MH-CoPES project

The approach adopted to conduct the MH-CoPES project was collaborative and participatory. Primarily, the aim was to use a consumer-directed approach. This was reflected in the overarching partnership between NSW CAG and NSW Department of Health, with the consumer and carer organisation, NSW CAG, funded to lead the project. The structure of the TWG was also reflective of the collaborative, consumer-directed approach that has been adopted: the TWG reflected a mix of the stakeholders involved in mental health services, and included strong consumer representation.

The approach to the project needed to be collaborative, participatory and consumer-oriented.

The principles underpinning consumer evaluation outlined in the following section, are also reflective of the approach adopted to conduct the project, and guided decision-making by the TWG.

2.2 The key activities of the MH-CoPES project

To achieve the overall aim and objectives of MH-CoPES, nine key activities were identified in the original project brief. These guided the progress of the project:

1. define clear criteria to evaluate existing tools, and/or develop new tool/s;
2. conduct a literature review on issues relating to the development of measures, methods and tools;
3. identify existing tools in use;
4. evaluate the tools identified;
5. produce an interim report for key stakeholders on outcomes of the evaluation;
6. obtain feedback from key stakeholders on the interim report;
7. modify tools based on stakeholder feedback and write a draft report;
8. hold a state-wide targeted workshop to comment on the proposed tool/s; and
9. produce a final report.

In addition to the original nine key tasks, the TWG added two further tasks that span the life of the project, which are:

10. Consult, inform and update key stakeholders; and
11. Evaluate the project.

2.3 Development of the MH-CoPES framework for consumer evaluation of mental health services and questionnaire

Four main methods were used to develop the MH-CoPES Framework for Consumer Evaluation of Mental Health Services and the draft Questionnaire. These methods are shown in Figure 1, and are reflective of the key project activities outlined in section 2.2 above.

2.4 Main findings from the literature review

Literature from a number of areas was reviewed. The main findings from the review are presented here, under the following headings:

Performance and quality frameworks

Satisfaction surveys

Consumers' perceptions and experiences of using mental health services

Recovery and wellbeing

Changing practice and culture.

The literature review.

Existing tools and processes.

The survey of NSW inititatives.

The consultations.

2.4.1 Performance and quality frameworks

Different frameworks or approaches to the task of considering, assessing and maintaining the quality of mental health care are available. The WHO [30] describes three approaches:

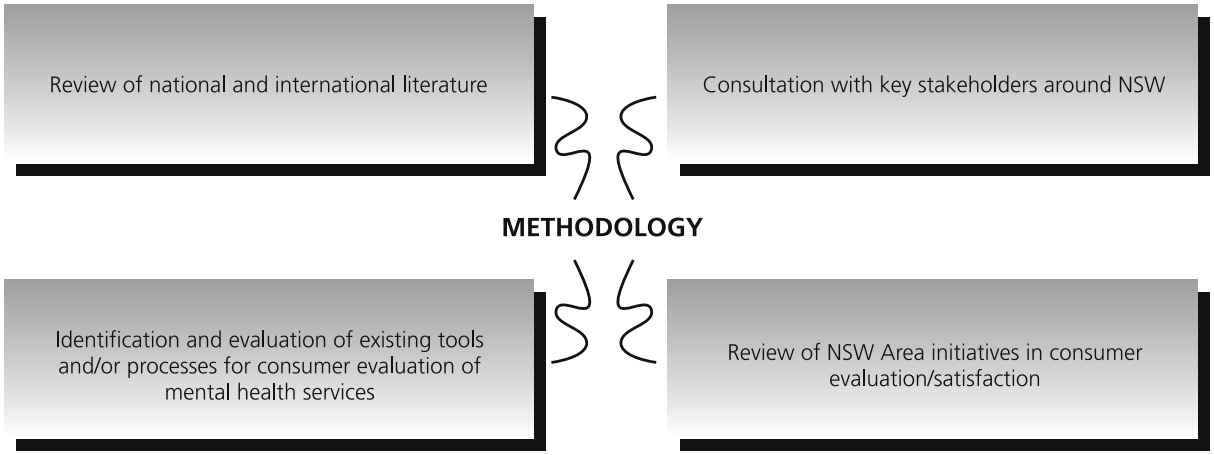

Figure 1. Methodology used to develop MH-CoPES Framework for Consumer Evaluation and Questionnaires

1. **Quality monitoring, or quality assurance.** The WHO states that quality monitoring has traditionally featured establishment of standards to which services can then compare their performance.

2. **Total quality management or continuous quality improvement.** This is synonymous with performance management and focuses on both identifying performance levels and ensuring that this leads to addressing problems and continuous improvement of the service.

3. **Balanced scorecard approaches.** The WHO states that balanced scorecards combine aspects of the previous two approaches, and are a mechanism that assists monitoring of performance across the multiple domains necessary in the mental health field.

Performance management systems integrate elements of measurement and monitoring systems into continuous cycles of improvement.[30] Performance management equates to a contemporary understanding of evaluation: that is evaluation must incorporate measurement, description, judgement, involvement of all stakeholders, repetition of evaluation cycles, and commitment to using the findings of the evaluation to implement and achieve change. [31, 32, 33]The key elements and principles of performance management are articulated in numerous ways, but generally revolve around a "plan–do–check/measure–act" cycle that is repeated.[34]

International efforts to develop performance management systems for mental health services, which incorporate information from consumers about their experiences of using services, include the Mental Health Statistic Improvement Program's (MHSIP) Mental Health Report Card (MMHRC)[35] developed in the United States. Another example is the resource kit of accountability and performance indicators for mental health services and supports, developed in Canada.[36]

2.4.2 Satisfaction surveys

Satisfaction surveys have been used extensively within both general health and mental health services internationally, as one of the primary means to elicit consumers' views of services. [37, 38, 39] A number of limitations with this method have become evident. Some of the problems with satisfaction surveys highlighted in the literature include:

Utility and sensitivity. The utility and sensitivity of consumer satisfaction surveys have been regularly questioned due to consistently high levels of satisfaction found when these surveys are used.[40, 41]

Accuracy. Different responses, or levels of satisfaction have been found when using a global measure of satisfaction compared to semi-structured interviews with the same consumers.[42]

Professionally developed, not consumer developed or oriented. Measures have often not been developed by consumers, based on issues relevant to consumers.[42, 43, 44, 45] Hansburg et al[44] found when administering a consumer developed survey versus a professionally developed survey, that satisfaction levels were lower when the consumer developed survey was used.

Administrator effects. Satisfaction with services has been found to be lower when consumers administer satisfaction surveys compared to when staff administer the surveys.[440, 44, 46, 47] A number of studies indicate that there is more complexity to this issue. Firstly, most of these studies report that high satisfaction was found across the board, whether staff or consumers administered the survey, although satisfaction was lower with consumer administration. Gill, Pratt and Librera[46] however, found that similar responses to those given with staff administration were noted at times with consumer administration, and suggest that when consumers who administer the questionnaire have greater power in the service, consumers' responses to the survey may be affected by the same factors as when staff administer these surveys.

The criticisms outlined above raise issues relevant to the MH-CoPES Project and our search for tools and processes for collecting and responding to consumer perceptions and experiences of mental health services. For example, it is clear that tools need to be embedded within transparent and systematic processes that address administration procedures. The importance of tools being based around issues pertinent to consumers, to ensure genuine opportunities for input into service improvement, is also evident.

A number of criticisms have been made of the construct of satisfaction itself, which guides this type of consumer survey. These criticisms revolve around the construct being too simplistic to adequately reflect consumers' evaluations, or inform services of consumers' perspectives:

> Evidence that consumers evaluate in different ways at different stages in their relationship with services. Generally, each contact with a service is part of a continuing series of interactions, and this is not considered in the satisfaction model underpinning these surveys.[48]
>
> Difficulties with the implicit assumption that people carry expectations, underlying the construct of satisfaction. Williams and Wilkinson[39] argue that "expectation plays a part in patient's evaluations of care, but at best the relationship is complex, and at worst, fulfilment of expectations may have little to do with expressed satisfaction." (p. 561).
>
> The complexity of consumer evaluation is not accommodated by the satisfaction construct. Williams, Coyle and Healy's[38] results indicate that, while consumers describe services in both positive and negative terms, there is a difference between consumers' value descriptions of their experiences of services, and their value descriptions of the services themselves. Williams et al[38] found that mediating evaluations of services are the concepts of "duty" and "culpability". What they found is that consumers may describe their experiences as negative, however not evaluate the service poorly. These authors found marked differences between consumers' responses during in-depth interviews compared to responses on satisfaction surveys. While during the interviews, consumers often reported negative experiences, their survey responses still tended to be either "satisfied" or "very satisfied". Williams et al[36] conclude that the construct of satisfaction does not hold much utility in terms of modelling how consumers evaluate services.

Ingram and Chung[3] raise a number of issues that may play a part in the background to the criticisms outlined. According to these authors, consumer satisfaction

measures are often used primarily to assist marketing and accountability processes, which leads to focusing on positive aspects. Ingram and Chung argue that, if these surveys are used to assist quality improvement/ planning processes, this should lead to careful focus on any dissatisfaction to help in planning change and improvement.[3]

The above critics agree that the solution needs to include:

- recognition that the satisfaction construct is too simplistic to accommodate consumers' experiences of services; and
- greater use of qualitative approaches to understanding consumer experiences and perceptions of services.[48] Swain-Campbell, Surgenor and Snell[49] provide evidence that more qualitative approaches in questionnaire format (that is open-ended questions) successfully identify areas which consumers believe need improvement that more structured formats do not elicit.

While satisfaction surveys have been used extensively in mental health services, it is important to note that some surveys used to collect information about consumers' views of services are not satisfaction surveys. Ford[50] makes the distinction between "patient surveys" and "patient satisfaction surveys". The first term indicates surveys used to elicit consumers' views and experiences of services while satisfaction surveys specifically adopt a satisfaction model of evaluation. It is apparent in the mental health services literature that the term "satisfaction survey" is also adopted at times to refer to surveys that are "consumer surveys" but not based on the satisfaction construct. Rather, these surveys ask consumers about their experiences and perceptions, often asking consumers to rank or rate their experiences without adopting the satisfaction concept. The literature reviewed here relating to satisfaction surveys raises a number of methodological issues that need to be considered, whether surveys are explicitly "satisfaction surveys" or not; however the theoretical criticisms are applicable specifically to those surveys underpinned by the satisfaction construct.

The review of the satisfaction literature provides additional support for the importance of performance management versus performance measurement alone. Reviewing the satisfaction literature also highlights some essential considerations for the process of collecting and using information about consumer perceptions and experiences of services, which can be summarised as including:

- evidence that a satisfaction model of evaluation is not suitable for use in this context, and is unlikely to produce useful information regarding negative views and experiences which is essential if the tool is to contribute to meaningful change;
- the importance of open-ended or qualitative approaches, in addition to more structured approaches to gathering information about consumers' views of services;
- consideration of administration procedures is essential when using questionnaires/tools to collect information from consumers about their views of services. Typically, involving other consumers in administration and support, rather than staff, will result in more consideration and feedback by participants about their negative experiences and views; and
- any tool used as part of a performance management system needs to ask questions relevant to consumers. This is likely to mean the tool is developed by consumers, or with considerable consumer involvement.

2.4.3 **Consumer perceptions and experiences of mental health services**

A solid body of literature exists that can be drawn on to help understand what is important to consumers of mental health services. There is clear evidence that consumers often perceive their own health and well being, as well as the mental health services they interact with, differently to staff, managers, carers and family members.[43, 45, 51.]

The literature describing consumers' views of, and experiences within, mental health services highlights a broad range of issues. These include:

staff attitudes and behaviours/relationships with staff[52, 53, 54, 56, 57, 58, 59]

power and control; empowerment and disempowerment[52, 53, 54, 55, 56, 57, 59, 60]

getting the services needed/availability and access[54, 58, 59, 60]

connectedness, isolation, family, friends and other consumers[52, 54, 55, 57, 59, 61]

being seen and responded to as a unique person [53, 55, 59]

information[55, 57, 60, 62]

clinical treatment, medication and alternatives, wellness models[54, 59]

support with other life achievements and needs, for example accommodation, work and vocational options, community activities. [53, 54, 57, 59]

Nelson, Lord and Ochocka[53] comment that indicators of service effectiveness have relied heavily on measures of hospitalisation and reduction of symptoms and suggest that: "these criteria reflect a focus on 'mental illness' rather than on mental health" (p. 137). The list above is a summary of issues raised in a selection of literature and is not exhaustive. The issues identified demonstrate the breadth of concerns that affect consumers' experiences of mental health services.

One important implication raised by the authors of the literature reviewed is that multiple meanings are adopted by consumers regarding what is important in a mental health service. As Epstein and Olsen[62] note, there is not "one" consumer voice, but a range of views and perspectives. This means that in developing genuinely participatory approaches to consumer evaluation of mental health services, opportunities for these different voices to be heard need to be created. One way to do this is to build qualitative methods for providing feedback, through open-ended questions on questionnaires, and through open-ended or semi-structured approaches to focus groups and interviews. Dialogue between consumers, consumers and services, and services and their communities will be a further important element of ensuring that differing voices are heard in the process of improving services.

2.4.4 **Recovery and well being**

Another body of literature important to developing a framework of consumer evaluation of mental health services relates to the areas of recovery and wellbeing. While the focus of the MH-CoPES project is on consumers' views of mental health services, rather than their views of personal recovery, consideration and understanding of the recovery construct is essential, given that many consumer leaders now define the purpose of mental health services as being to facilitate recovery.

The National Mental Health Plan[15] states as one of its underpinning principles that: "a recovery orientation should drive service delivery" (p. 11). The basic assumptions of a recovery-focused mental health system, described by Anthony[11] involve: a belief that consumers hold the key to recovery, not professionals; that mental health workers may provide support to consumers, however, recovery is just as possible without professional intervention; that good, human, relationships are one important facet of the recovery process; that recovery is not a linear process; that recovery is also about consequences of the illness, not only symptoms; that the concept of recovery is not synonymous with removal of all symptoms, which means recovery can occur even though symptoms recur.[11] A recovery orientation fits within broader health or well-being conceptualisations[63] as opposed to the deficit approach which underlies the more traditional medical model.[64, 65] These perspectives emphasise consumers' strengths and assets, and place consumers' views centrally in their own lives, and in effective mental health services and research.[66, 67]

Recovery has its roots in the consumer movement, and so is especially important to MH-CoPES. Fisher,[68] Executive Director of the National Empowerment Centre in the United States, uses a tree metaphor to explore the concept

of recovery. He describes the ground as shared humanity; the seed of the tree, spirit; and the roots, connections. Fisher describes the trunk of the tree as body, mind and soul, with branches being a sense of self and voice. The limbs of the tree reach out to give fruit to self and others: love, courage, self-esteem, pride, hope and meaning. A summary of themes from four studies exploring recovery or wellbeing from consumers' perspectives are presented in Table 3.

Table 3.

Summary of themes from four studies focusing on consumer defined recovery and wellness

Authors	Svedberg, Jormfeldt and Arvidsson[71]	Gordon, Ellis et al [22]	Ahern and Fisher[10]	Tooth, Kalyanasundaram, Glover and Momenzadah[72]
Origin	Sweden	New Zealand	US	Australia
Focus	Consumers' conceptions of how health processes are promoted in mental health nursing.	Domains that consumers, across cultures, have identified as being important in terms of their mental well-being, identified through consultation with consumers in New Zealand and comprehensive examination of the recovery literature.	Major themes highlighted as forming a recovery and empowerment culture in the National Empowerment Centre's research into recovery.	Consumer perspective on recovery from schizophrenia. Reporting factors most frequently reported by people as important in their recovery.
Themes/ Domains	**Interaction** To trust To feel mutuality To enter into a personal relationship Attention (paying attention to consumer as important individual) To feel noticed To feel the nurses commitment To feel the nurse is accessible **Development** To gain hope To see new possibilities To have one's good qualities recognised To obtain knowledge To be confirmed **Dignity** To have the right of self-determination To feel respected	Relationships, trust, connectedness, taha wairua/whanau, whannau/family support, social support, interdependence; Day to day functioning, coping and managing, including work (having the ability to work), taha tinanan; Connection to one's culture, cultural identity, drawing strength from one's culture, taha wairua; Physical health and health risks, taha tinana, includes alcohol and drug use, side-effects of medications, sleeping and eating; Quality of life, life satisfaction, enjoying the environment, feeling alert and alive, able to enjoy pastimes/ hobbies; Illness symptoms, taha hinengaro; Coping with and recovering from illness, self-managed care, staying out of the mental health system, understanding of illness; Hope, journey from alienation to purpose, reawakening of hope after despair; Empowerment, being in control, exercising choice, positive sense of self, self-determination; Spiritual strength, increased spirituality, taha wairua; resources, basic needs (eg: food, money, transport); and Satisfaction with services.	Relationships Beliefs Self/identity Community Skills	Determination to get better; Finding their own way to manage their illness, Recognition of need to help themselves, having friends who accept them, negative aspects of medication, Negative impact of health professionals accepting the illness, life disruption caused by illness was a life-transforming experience, Friends affirming the person, Struggled with ability to recovery, affirmation received from support groups, achieving something was important, support from health professionals, Stigma hindered process, understanding illness was important, Pre-illness strength helped, Emotional support from family, Hospital did not help.

Reviewing a number of studies with a focus on recovery and well being demonstrates that a much broader and encompassing focus is needed, rather than a focus on 'symptoms' and 'hospitalisation'. As Nelson et al[53] suggest, from consumers' perspectives, service quality and the impact of delivery needs to be considered from a more wholistic, "mental health" focus rather than from a "mental illness" focus. This view is supported by earlier studies conducted in Australia and internationally that reviewed self-report outcomes measures, which have found that many outcomes measures currently in use are not appropriate, and do not reflect consumers' requirements, particularly in terms of breadth of domains or themes covered.[22, 55, 69]

A question that arises from this type of review and conclusion is whether services *are, or should* be, accountable and judged, based on such a broad range of domains. The different emphases placed on aspects of health, and experiences within services by consumers, compared to other stakeholders, have already been highlighted in the above review. Siggins Miller Consultants[55] also raise these questions in their review relating to self-rated outcomes measures, and highlight that areas of research such as "spontaneous recovery" in depression and alcohol dependence emphasise the therapeutic importance of changes in life circumstances like housing, or employment, over more traditional approaches such as medication. While authors like Steadman et al[69] argue that services should not be held to account for things outside their stated focus, others such as Nelson et al[53] argue in contrast. They suggest that policy changes need to occur to ensure that these broader domains are within mental health services scope, given their importance to consumers.

In identifying existing tools and processes for services to hear and respond to consumer perceptions of service delivery (see section 2.5 below), two tools were identified, based firmly in a recovery-orientation.[72, 73, 74] These approaches explicitly evaluate the availability, quality and effectiveness of services from a recovery-orientation.

Campbell[1] reports that forty-seven percent of consumers interviewed as part of the Well-being project in the United States reported that they had avoided traditional mental health services because they viewed these services as having negative effects on their well-being. It is evident from the study that consumers need an opportunity to report on a broad range of issues that relate to their perceptions and experiences of mental health services, including views of service delivery, to ensure that services fit with consumers' definitions of recovery and well-being.

2.4.5 **Changing practice, changing culture**

Mental health care has been the focus of continuing change over recent years.[75] Being regularly expected to adapt to changing work practices can be difficult for professionals.[76] Additionally, there is substantial evidence from both the public and private sectors that achieving fundamental change is difficult in organisations, and that interventions aimed at achieving organisational change rarely meet initial expectations. [77] At the same time, however, the centrality of change in nursing practice is well acknowledged within the literature.[78] Tingle[78] notes that, while there is substantial literature exploring barriers to change, less is available scrutinising aspects of current practice that "are ripe for change" or addressing the factors which can facilitate change in the nursing field.

Part of the vision of MH-CoPES is to develop a mechanism by which consumers' views contribute to service change and improvement. Therefore, adoption of the MH-CoPES Framework will result in more change for staff in mental health services. In fact, the process will assist in determining expectations for change, and provide guidelines for how and where changes need to occur. It is also likely that implementation and adoption of MH-CoPES will challenge the dominant medically oriented culture of mental health services. In articulating the *Framework for Managing the Quality of Health Services in NSW*,[17] the NSW Department of Health also recognised the centrality of culture change. For MH-CoPES, this means that understanding how change occurs within the health

professions and mental health services is essential to developing a robust framework for consumer evaluation of the services. The framework needs to utilise known approaches to facilitating change and improvement.

Several factors are highlighted as important to driving change in mental health practice. These include: consultation and communication, a sense of ownership, organisational culture, and credibility.[76, 79, 80] Each of these is examined briefly below:

1. Consultation and communication.

Kaner and colleagues[76] argue that communication and consultation needs to be personal, with information flowing in both directions between those people involved in order to facilitate change. In mental health services, and for MH-CoPES, this communication flow needs to occur between health services and consumers; between consumers and health services; and between consumers. The aim of MH-CoPES Stage 1 is essentially to develop a framework to aid communication within services, providing one further mechanism to assist the flow of information between these groups, and an additional means for consumers to communicate their views to health services. MH-CoPES centrally aims to encourage dialogue between these groups of people around issues that are important to consumers concerning service delivery, particularly areas that may be problematic.

The development of shared understanding between services and consumers was found to be a central issue in achieving change in the 'Understanding and Involvement Project'[26]: "unless [there are] opportunities for staff to receive and discuss that feedback, and clarify meanings and consequences for action in conversation with consumers, then little might be forthcoming in terms of change as a result." (p. 178). Any data collection tool in itself can contribute only partially to building dialogue between the key stakeholders in mental health services. The process that describes how the tool is implemented, how reporting of the data collected should occur, and what and how steps should be taken to address issues raised are essential to building these opportunities for dialogue.

2. A sense of ownership.

A number of authors highlight a sense of ownership as central to change.[76, 81] A sense of ownership links to how relevant the tools (and domains covered by the tools) are at local and service levels. As well, perceptions of whether the tools and the changes indicated fit with mental health workers' ideas of what is important will influence a sense of ownership. This highlights the point that in developing the MH-CoPES process, the action phase should be driven at local levels; local solutions and local action needs to be facilitated in response to the recommendations for change.

3. Organisational culture.

Organisational culture has long been recognised as a factor involved in organisational change.[76, 80] In mental health services, perhaps one of the key questions to ask is: *how much is the organisational culture influenced by the medical model, which excludes consumers as important sources of knowledge and expertise*?

The dominant organisational culture in health and nursing revolves around the notion of expertise, which rests with clinicians and does not acknowledge consumers. The organisational culture across health and mental health is that the consumer is helpless and/or in need of help, and this places them at the bottom of the organisational hierarchy. The MH-CoPES tools and processes are one way to challenge this cultural position. MH-CoPES aims not only to give consumers a voice, but also a way for service staff to be able to hear more clearly what consumers find beneficial when using services, and what might need to change. This can facilitate an opportunity for service staff to review and improve their practice.

4.Credibility.

Fitzgerald et al[79] highlight the centrality of professionals' views of what is credible as one basis from which change occurs. They note the growing evidence that different groups of professionals hold different concepts of what is credible. These authors point out that credibility is not a

straightforward judgement, simply based on perceptions of the quality of research that indicates a need for change. At the core of MH-CoPES is a statement that consumers' views are credible to guide service delivery and change. This perspective is in direct contrast to the dominant organisational culture discussed above. MH-CoPES, then, may challenge mental health workers' concepts of what is credible.

Systematic analyses and review of interventions aimed at improving or changing the performance of health care professionals demonstrate a wide range of approaches available.[79] The types of interventions identified include:

- educational material;
- conferences;
- audit and feedback;
- local opinion leaders (providers explicitly nominated to be educationally influential);
- patient-mediated interventions;
- reminders (ie. regular prompting);
- outreach visits (trained person who meets with health care providers);
- marketing (designing interventions based on interview, focus group or survey feedback from providers); and
- local consensus processes.

In general, active approaches to behaviour change are more likely to be effective, whereas passive approaches (for example, mailing staff educational material) are generally ineffective and unlikely to result in behaviour change.[81] There is strong evidence that multifaceted approaches are more effective than single interventions.[82, 83] Oxman et al[82] suggest that: "many interventions have modest or negligible practical effects when used alone. However, when coupled with other strategies the effects may be cumulative and significant." (p. 1427).

2.5 **Identification of existing tools and processes for consumer evaluation**

In total, 20 tools and processes were identified from the literature review conducted, and represent national and international efforts to produce instruments and processes for mental health services to hear and respond to consumers' views.

The literature review.

Existing tools and processes.

The survey of NSW inititatives.

The consultations.

In identifying tools and processes for consideration, the TWG explicitly sought work that focused on measuring and responding to consumers' views of mental health services. Tools specifically designed for use by child and/or adolescent consumers, adults and older consumers were also identified, and some of the tools identified are available in formats for use with more than one of these age groups. One tool (the Community Living Skills Scale) is more specifically a traditional "consumer outcome" measure, however it was developed by consumers and was thus included for consideration by the MH-CoPES TWG small working party involved in evaluating the tools and processes identified. In addition, the WHO Quality of Life brief measure (WHOQOL-BREF) was also included.

While a range of other tools were identified through the literature review, these were excluded from further consideration. These included:

1. Satisfaction scales: the SERVQUAL;[84] Client Satisfaction Scales (CSQ; CSQ-8);[85] the Service Satisfaction Scale (SSS),[87] the Verona Service Satisfaction Scale (VSSS)[87]; the General Satisfaction Questionnaire (GSQ); the Patient Satisfaction Questionnaire (PSQ);[88, 89] and the Patient Judgement System (PJS).[90]

Many of these satisfaction instruments were developed for use in general medical or hospital settings, or to measure satisfaction with a wide range of organisations/

Table 4.

Tools and processes identified for consideration by MH-CoPES project

Tool and/or process	Country of origin
Accountability and performance indicators for mental health services and supports[36]	Canada
Carers' and Users' Expectations of Services – User version. (CUES-U)[51]	UK
Community Living Skills Scale (CLSS)[93]	USA
Consumer Assessment of Behavioral Health Services instrument (CABHS)[94] *	USA
Consumer Evaluation of Mental Health Services (CEO-MHS) – Evaluation Framework and CEO-MHS- 26 [95] *	Australia
Consumer Expectations, Perceptions and Satisfaction Scale (CEPAS)[96]*	Australia
Consumer Satisfaction of Parents and their Children[97]	USA
Inpatient Evaluation of Services Questionnaire (IESQ) [98] *	Australia
Mental Health Statistics Improvement Program (MHSIP) Consumer Survey[35]*	USA
The Multidimensional Adolescent Satisfaction Scale (MASS)[99]	USA
Patient Perception of Hospital Experience with Nursing (PPHEN)[100] *	USA
Recovery Oriented System Assessment (ROSA)[72]	USA
Recovery Self-Assessment (RSA) [73, 74]*	USA
Rome Opinion Questionnaire for Psychiatric Wards (ROQ-PW) [101]*	Italy
Satisfaction with Nursing Home Instrument (SNHI) [102]*	USA, Korea and Taiwan
The U and I Model: A model for increasing evaluation of acute psychiatric hospital practice [25]*	Australia
User Focused Monitoring (UFM) [103]*	UK
The Victorian Consumer Survey [104]*	Australia
WHOQOL-BREF[105]	Multi-national
The Youth Client Satisfaction Questionnaire (YCSQ) [106]	USA

NOTE: *indicates tools used as item pool for consultation and development

services. These tools were excluded from consideration by the TWG because of the range of issues our literature review highlighted relating to satisfaction scales and the satisfaction construct.

2. Outcomes measures: the Behaviour and Symptom Identification Scale (BASIS-32);[91] Mental Health Inventory (MHI); SF-36;[92] and the K-10.

These tools were not included for consideration, for two major reasons:

These tools are more specifically focused on outcomes/ symptoms rather than views of services.

These outcomes measures have been identified in previous studies focusing on consumer outcomes measures as inadequate when evaluated against consumers' requirements for outcomes measures.[22, 55.]

The tools and processes identified through the literature review are listed in Table 4.

2.6 Initiatives in consumer evaluation/ satisfaction in NSW services: the survey

Twelve tools and processes were identified by conducting a survey of mental health services across NSW, both government and non-government agencies (NGOs). Of these 12 tools, one was also identified by the literature review. The survey was conducted during the first half of 2004. While the scope of the MH-CoPES project did not extend to NGOs, the TWG agreed that this sector was important to engage with, and learn from, and so it was agreed to survey NGOs as well as AHS, mental health services.

The literature review.

Existing tools and processes.

The survey of NSW inititatives.

The consultations.

The aims in conducting this survey were multifaceted, including, to:

1. find out what services in NSW currently do to collect and use information about consumers' views of services;
2. identify tools and processes currently in use in NSW;
3. find out what services identify as the benefits and limitations of collecting and using this information;
4. inform mental health services across the state of the MH-CoPES Project; and
5. establish a contact person in each service for further liaison and consultation with the MH-CoPES project team.

2.6.1 Developing the survey for AHS mental health services and non-government mental health organisations

The survey was initially drafted by a small working party from the MH-CoPES TWG. This draft was then modified based on feedback from the larger TWG and the Centre for Mental Health, NSW Department of Health. Surveys were posted to services with a covering letter from Professor Beverley Raphael, the then Director of the Centre for Mental Health, and Douglas Holmes, Executive Officer of the NSW CAG. This introduced the MH-CoPES project and described the aims in conducting the survey. The letter was addressed to the Area Mental Health Director of public mental health services, and to the CEO or Manager of NGOs.

A total of 55 surveys were posted to services across the state. Nineteen AHS, mental health services (AMHS) and 27 non-government organisations (NGOs) were sent a survey, with nine surveys from the total of 55 sent to alternative sections of these organisations. NGOs were identified through the Way Ahead Directory[107] and Mental Health Coordinating Council's list of members.

2.6.2 Findings from the survey: what is occurring in mental health services in NSW to collect, collate, report, and respond to consumers' views of services?

Thirty-five surveys were returned, 18 from NGOs and 17

from AMHS. Thirty-one organisations reported that they did collect information about consumers' views of services (17 NGOS; 14 AMHS), while four organisations reported that they did not collect this type of information (1 NGO, 3 AMHS).

In those organisations that reported collecting information about consumers' views of services, the responses indicated that this data collection occurred to various levels and in different ways within organisations. For example:

• One AMHS indicated that they collected this information as part of a "one-off" research project; and

• Two AMHS indicated that while sections of their services did collect this information, other sections did not.

The four organisations that reported not currently collecting this type of information reported barriers related to:

finding appropriate tools and methods to collect this type of information;

low consumer interest or advocacy; and

lack of resources available to conduct this type of information collection, and use it appropriately.

Of the 31 organisations that reported collecting this type of information in their services:

Twenty-six organisations reported that they use a specific tool (questionnaire) to collect this information with consumers.

in addition, many reported using other methods as well. These include: Consumer Consultants interviewing consumers; community forums; informal interviews with consumers; feedback forms; suggestion boxes; consumer meetings; documented complaints registers.

most organisations reported using tools designed "in-house" (11 responses explicitly stated this). One NGO reported adopting a tool designed by the local AMHS; and 5 organisations indicated they use published tools or an adaptation of a published tool.

two respondents indicated that the tool they currently use focused on evaluating a specific aspect of the service, or a specific project being conducted – not the services more broadly.

the TWG received information about 12 specific tools which were sent with the completed surveys which are summarised in Table 5.

Five survey respondents reported using alternative methods to collect this information, which included:

using a variety of methods developed for specific purposes and sections of the service;

consumer advocates collecting information on an ad-hoc basis;

weekly consumer meetings where issues are discussed and actions agreed upon.

Organisations indicated that they use results obtained from consumer surveys in a number of ways, including:

reporting to funding bodies, management and consumers;

accreditation purposes and to meet the national standards;

reporting to specific committees to develop recommendations and action based on the results;

suggested changes discussed at meetings attended by consumers and staff;

informing the service about areas of concern for consumers;

reviewing service delivery, identifying gaps and areas of need / service quality improvement;

staff training purposes; and

as part of individual service plans.

Table 5.

Tools identified through MH-CoPES survey of mental health services in NSW

Instrument/process	Provided by
The Chisholm Ross Centre Satisfaction Survey	Southern Area Mental Health Service
Consumer Shaping Mental Health Services Interview Procedure	Southern Area Mental Health Service
Early Psychosis Intervention Service Consumer Satisfaction Survey	Northern Sydney Area Mental Health Service
The Hunter Mental Health Consumer Evaluation of Services Questionnaire	Hunter Area Mental Health Service
Macquarie Hospital Patient Satisfaction Survey	Northern Sydney Area Mental Health Service
Mid-West Area Mental Health Service Client Satisfaction Survey	Mid-Western Area Mental Health Service
Northern Rivers Mental Health Council Client Satisfaction Survey	Northern Rivers Area Mental Health Service
Northern Sydney Health Satisfaction Survey	Northern Sydney Area Mental Health Service
Ryde Consumer Network – Consumer Satisfaction Survey	The Ryde Consumer Network
Inpatient Evaluation of Services Questionnaire (IESQ) [98] (see Table 4)	Central Sydney Area Mental Health Service
Braeside Aged Care Psychiatry Consumer Satisfaction Survey	Braeside Hospital, Aged Care Psychiatry, South West Sydney Area Mental Health Service
Braeside Aged Care Psychiatry Patient Questionnaire	Braeside Hospital, Aged Care Psychiatry

NOTE: Area Health Service amalgamations occurred 1st January 2005. Area Health Services listed in this table are prior to amalgamations.

2.6.3 **Themes and lessons from the responses**

A number of themes and lessons are evident from the results of this survey regarding what is currently occurring in NSW to collect, collate, report and respond to consumer perceptions and experiences with mental health services.

Particularly evident is the lack of clarity between collecting consumer-rated outcomes, and consumer perceptions and experiences of the services.

The survey provided an opportunity for respondents to provide any other comments or feedback, and many participants chose to use this section. Some of the issues raised here included:

- support for the MH-CoPES Project, or the concept of a state wide approach to hearing and responding to consumers perceptions and experiences;
- the difficulties in ensuring accuracy:
  - making sure consumers are able to answer honestly and are not answering these types of surveys in a manner specifically to please staff;
  - accommodating varying literacy levels, possibly through providing different formats such as verbal as well as written;
  - the need for service staff to be trained to ensure the process is consistently followed, and that there is a full understanding of the principles of consumer participation amongst staff;
  - the need to ensure a way of addressing specific needs of different groups, for example older clients or children, as well as different service settings.
- the need for a prompt mechanism for feedback to services regarding results so action can follow in a timely manner.

While some services commented on the difficulty they had found to date in getting responses from consumers to their surveys or feedback-seeking initiatives, many reported finding the information they already collect invaluable to service planning.

2.7 An evaluation of the tools and processes identified through the literature and the survey

An evaluation of the 30 tools and processes was conducted by the TWG. Each was rated against a set of criteria established, based on the domains identified in the original project brief, which were: access to services, availability of services, treatment and assistance, staff/ consumer relationships, getting information, participation and hospital care. Additionally, the TWG considered the length of tools and number of items, the type of response scale and appropriateness of this for our culture and population, settings addressed by the tool (ie. child, adult, older, plus inpatient or community etc), and the psychometric properties known about the tools. The TWG also assessed how the tool had been developed, and what consumer input and collaboration was involved for each.

The TWG found that primarily the examples identified were tools, the majority questionnaires or scales. Only a few examples of frameworks addressing issues of consumer evaluation of mental health services were found, including the Understanding and Involvement project,[26] the Consumer Evaluation of Mental Health Services (CEO-MHS)[121] work, the User-Focused Monitoring[103] work, and the MHSIP[35, 122] consumer evaluation work. It was agreed that these models all offered important information to development of a framework of consumer evaluation in NSW, however, none of these were appropriate for adoption by NSW Health.

The evaluation resulted in a decision that MH-CoPES would develop an integrated framework and tools, suitable for NSW mental health services. It was determined that during Stage 1, development of a questionnaire would be the focus of tool development with items from a number of tools identified in this review (identified by * in Table 4) forming an item-pool to generate discussion and prioritisation during consultations with key stakeholders.

2.8 Key stakeholder consultations

During 2004 and early 2005 11 consultation forums were conducted around NSW in two stages. A list of these forums is provided at Appendix C. These consultations were held in two phases: the first focused on developing a questionnaire from the item-pool and stakeholder input, while the second phase of consultations reviewed the draft questionnaire developed. Discussion of the Framework occurred in both phases.

During Stage 1 of consultations, participants were invited to assist in the questionnaire development, by prioritising possible items that had been identified in the review of existing tools. This iterative process resulted in 330 possible questionnaire items being reduced to a prioritised list of 88 preferences, chosen by stakeholders across seven consultation workshops. The TWG then worked with this set of 88 items, to develop a first draft of the Questionnaire (one inpatient version, one community services version). These versions of the Questionnaire consisted of 34 and 33 items respectively. Ninety stakeholders participated in these consultations, and approximately 56% of those people who participated were consumers. Others who attended included service staff, NGO staff, Official Visitors, local councillors, representatives from local divisions of general practitioners, and carers.

The literature review.

Existing tools and processes.

The survey of NSW inititatives.

The consultations.

A second draft of the Questionnaire was then produced, through the feedback received during Stage 2 consultations. In these forums, draft 1 was reviewed. Participants were asked to provide critical feedback on the positive and negative features of the Questionnaire. Suggestions regarding what to remove, rephrase or add

were sought, as were any other comments. Sixty-three stakeholders attended Stage 2 consultation forums, and of these, approximately 43% were consumers. Other stakeholders included service staff and managers, carers, volunteers in the sector, NGO staff, police and GPs.

Along with these Stage 2 consultation forums held in local areas, a state wide workshop was held in Sydney in early April 2005, at which more feedback regarding draft 1 of the Questionnaire was sought. Approximately 80 stakeholders participated in the workshop.

2.8.1 **Phase 1 consultations**

Between September and the end of December 2004, seven consultation forums were held in different parts of the state, to gain input from key stakeholders about the issues involved in consumer evaluation of services, and to assist in the identification and development of appropriate tools to support the process of evaluation. These consultations were held in Bega, Yass, Broken Hill, Port Macquarie, Morisset, Griffith and Tamworth. A range of stakeholders attended each forum, with consumers, carers, staff, NGOs, and allied health professionals all represented. Between five and 30 people attended any single forum.

Generally, the major challenge for MH-CoPES, and consumer evaluation of mental health services, relates to the multiple viewpoints of stakeholders. At a simplistic level, this can be seen as lying at the interface between being consumer oriented versus being service oriented, with perceptions of what is trustworthy and useful from each of these orientations key. However, the feedback from consultations indicated that even within stakeholder groups, there are different and divergent perspectives of what is needed, and what is appropriate, in terms of evaluating mental health services.

Table 6.

Barriers identified in Stage 1 key stakeholder consultations

Barriers to consumer involvement
Fear of negative repercussions
Not every consumer will be interested in providing feedback to services
Choice and flexibility in how to give feedback: having options, multiple tools
Lack of support/ need for support
Burden: eg: length, time required
Differences in the way services are accessed and used: rural versus metropolitan differences.
Privacy: when and where asked to take part
Service/System level barriers
Devaluing of non-professional's views – not taking consumers' perspectives seriously: a culture of valuing only particular types of information
Limited understanding of what "partnership" means and how it is enacted
Recovery rhetoric versus reality in services
Quality: not seen as everyone's business and routine practice
Fear of change within service
Lack of resources, and a perception that "this is too expensive"
Different levels of need within and between services for information
Lack of support for on-the ground staff
Short-staffing

2.8.1.1 Barriers to consumer evaluation of mental health services

A number of barriers that may affect consumers and services, impacting on successful implementation of MH-CoPES were highlighted by participants in consultation. These barriers are summarised in Table 6.

Fear of negative repercussions. Consumers identified a fear of the consequences of providing negative feedback as a major disincentive for them and others, and some participants spoke of real examples where they had previously experienced negative consequences because of speaking out, or had witnessed this occurring to others.

Lack of interest, or limited understanding about participation. Participants identified that not all consumers will be interested in providing their feedback to services. This could reflect a general lack of interest held by an individual, or may be a contextual issue, relevant at one point in time for a person. The common but unrealistic assumption that consumers will unanimously want to be involved in evaluating mental health services is also raised in the literature, by authors such as Lammers and Happell[109] and Tobin, Chen and Leathley.[110] As well, participants suggested that many consumers may not have a clear understanding of participation and the importance of consumer feedback.

It was acknowledged that some consumers, particularly depending on their history and experiences with the services, will perceive MH-CoPES as token and "a waste of my breath." This attitude will have real implications for the success of MH-CoPES implementation, as this relies on all stakeholders genuinely engaging in the evaluation process.

Choice, or lack of choice, in how they can take part. Participants identified that the choice and range of tools available, and administration methods from which they can choose, would impact on whether or not consumers engage in evaluating the services. Discussion in consultations raised points including:

- the language used in questionnaires or interview methods;
- options to give verbal rather than written feedback;
- consumers' literacy skills;
- cultural in/appropriateness of tools and questions asked;

as some of the factors that will affect consumers' choice (and at times ability) to take part. Stakeholders, during consultation, discussed the view that a range of administration methods will be necessary, with a general view evident amongst consumers that while questionnaires have an important place in their choice to evaluate services, they have limited utility and are often viewed as likely to be tokenistic. Participants described seeing questionnaires as limited in terms of being able to get to a clear view of what consumers mean when they discuss their experiences of mental health services, suggesting that questionnaires are limited because of the inevitable constraints on what answers can be given. A concern that, often, consumers feel a fear of "getting it wrong" when asked to fill out questionnaires was also raised.

In general, open-ended or qualitative methods of data collection were advocated as more useful and appropriate ways of consumers' giving input and feedback to services, however this was not a completely clear-cut issue. Consumers spoke about the importance of choice, and discussed how, at times, they would prefer to complete a questionnaire, but identified other periods of time when they would choose a more open-ended option through which to give their feedback. Participants suggested that both qualitative and quantitative methods should be available to consumers to choose from.

Lack of appropriate support to take part. Participants in consultations made it clear that there were times when consumers may require support to participate

in evaluating the services they use. If an equitable process is to be developed, they suggested that personalised support, with the option to give feedback verbally was essential. Participants reinforced the importance of this being from a consumer-perspective. Repeatedly, consumers acknowledged that the most appropriate form of support would be to have consumer interviewers. Some participants suggested that consumer consultants may be able to perform this task. Consumers also noted that they may choose to be supported by family, friends or carers to complete a questionnaire, and a process flexible enough to allow this would be essential to MH-CoPES' success.

The burden taking part in evaluation may place on consumers. Things like the length of questionnaires could affect burden, or the time involved in being interviewed. As well, issues such as when consumers would be expected to give their feedback, and if they can choose a time and place they are comfortable with will impact on perceived and real burden.

Differences in the way services are accessed and used. Differences between rural/remote and metropolitan services, and how consumers interact with them, were particularly highlighted. Participants in rural and remote areas suggested that the challenges inherent in accessing services in their areas will also become a major challenge for implementing MH-CoPES successfully.

Issues of privacy were raised as key issues and possible barriers in consultation. For example, when and where will consumers be asked to take part, and by whom. Timing in terms of being in hospital was discussed as pivotal in consultations also. Consumers and other stakeholders identified that this is an important time to inform consumers about MH-CoPES and their right to be involved in evaluating the services, however, this is seen as a particularly sensitive time in terms of asking consumers to take part. A number of issues were raised in discussion about this:

Many consumers stated that their experience has been that they are not well enough to actively take part in completing a questionnaire at discharge (and may or may not be able to take part in an interview at this stage)

A fear of being kept in hospital if any negative feedback is given was perceived to be a barrier that would either stop many consumers from taking part at this point, or result in positively skewed results.

A number of barriers at a service or systems level were also identified as challenges for consumer evaluation of mental health services. At the core, most of these barriers relate to attitudes and culture within services, and it was suggested that broadly, these need to change for MH-CoPES to be successful.

Some of the specific attitudinal or cultural issues raised in consultation included:

Devaluing of non-professionals' viewpoints – not taking consumer perspectives seriously. Participants in consultation expressed the view that consumers' views are still often not taken seriously by mental health services. This view is supported by recent studies, which provide clear evidence that mental health workers "may still be unwilling to trust and respect the patient view,"[110] or recognise that consumer input can bring valuable contribution to service planning, delivery and change.[109]

Perkins and Repper[111] have identified five major barriers to the inclusion of consumer voice in mental health services, which are:

- dismissal of consumer voice because consumers are diverse: there is not an homogenous, agreed 'consumer' perspective;
- participation seen as 'icing on the cake' rather than 'the cake itself' – therefore limited resources are allocated;
- tokenism: consumers fit into existing committees,

without opportunities to shape and change what is happening;

- humouring or patrony where people listen but do not hear and respond; and
- assumption by professionals that views and opinions of consumers reflect their psychopathology so they can 'interpret' what is really meant.

There is strong agreement that overcoming the barriers to genuine participation requires "ongoing structural and cultural change."[19, 27, 112]

Limited understanding of what 'partnership' means and how it is enacted. From participants' experiences with services, it was suggested that partnership is still not well understood or carried out in services, and this barrier relates directly to the barrier above.

Recovery rhetoric versus reality in services. There is increasing rhetoric around recovery-oriented services reflected in state and national policy, however, the literature indicates that there is still a gap between policy and practice. Participants in consultation also discussed this gap between the rhetoric and reality of recovery orientation. One of the core issues links back to where mental health services have come from: grounded in the medical model of mental illness. There is a significant conceptual difference between "mental health" and "mental illness". Stakeholders in consultation highlighted this as one of the areas that will challenge MH-CoPES, suggesting that services currently tend towards being reactive rather than proactive, and despite their name, based on "mental illness" not "mental health".

Stakeholders argued in consultations that MH-CoPES should contribute to building concepts of mental health – providing services with information that will assist them in being proactive by assisting services to understand what supports wellness for consumers. Participants argued that consumer evaluation should be grounded in the recovery perspective, a view also held by the TWG, and outlined in the underpinning principles of MH-CoPES. Linked to this were discussions about consumers as whole people, and the need for holistic models and approaches to guide services. MH-CoPES should also support holistic views of consumers.

Views of what quality is and where it fits into everyday practice. Participants in consultation suggested that quality activity is not often seen as a core part of everyday work in mental health services, and is often viewed as distinct from the treatment and care provided. Fletcher[113] provides support for this view, noting:

> *The Taskforce on Quality in Australian Health Care… noted that, despite an increased emphasis placed on quality improvement in health care, activities labelled 'quality related' have in general been marginalised in the delivery of clinical care.*

This will pose a barrier to MH-CoPES, if service staff in general view ensuring quality services as someone else's job.

A fear of change within services. Concern that "if we do it we might have to do something about it". Participants in consultation held the view that services often would rather not know what consumers think because of the obligation to act, based on this information.

Concern that change will not be supported. Participants identified that adequate leadership and support will need to be available to create changes that the evaluation process suggests are necessary. It was recognised that creativity is essential in implementing any continuous improvement. Creative solutions may be simple solutions, or alternatives to what has normally occurred, but may not always mean greater expense is needed for positive changes. For example, Schwappach et al[114] report on the effective use of changing information and communication approaches to address consumers' negative views of waiting times in an emergency setting. Participants in consultations stressed

that often more information about what will happen and why could assist in creating a different experience of services for them.

Differing concepts within and between services of what level of information is required to be useful. It was suggested that this may particularly pose a barrier in terms of developing and implementing a coherent state-wide approach to consumer evaluation of services. One area of major difference was suggested to exist between rural and remote services versus metropolitan services in NSW.

Professional valuing of only particular types of information. Participants suggested that within services there is a general valuing of quantitative or quantifiable information over qualitative information, accompanied by the view that high response rates are essential to ensure the information is valid. Participants in consultation saw this as linked to the medical emphasis in services – the "mental illness" focus rather than one of "mental health and recovery". Satisfaction surveys and questionnaires, however, are well known to achieve low response rates, and the barriers identified by consumers above provide some insight into a range of reasons why this might occur.

Affecting the level of response attained may be the degree of anonymity and confidentiality achieved and maintained. If follow up of participants cannot be conducted anonymously research suggests there will be significant cost to response rates. Telephone use is the primary form of low-cost follow-up evident within the literature, with demonstrated impact on response rates.[115, 116, 117] However, if it is not known who has returned a questionnaire and who has not, two options are available. All consumers could be telephoned, and reminded, with an apology if they have already completed and returned a questionnaire, which is a time consuming and costly option; or no telephone reminders could be made at all, which will cost in terms of lower response rates.

A perception that on-the-ground staff are not valued and supported by higher level management, which results in high levels of burnout and low staff retention, making implementation of the process of evaluation and changes to service provision difficult.

Problems of short staffing (often perceived in terms of lack of time or resourcing) was identified to be a significant practical and psychological barrier to implementation of MH-CoPES if service staff are expected to assist in disseminating, supporting and/or following up MH-CoPES feedback from consumers.

2.8.1.2 Overcoming the barriers and identifying factors that support consumer evaluation in mental health services

Participants involved with the consultations made a number of suggestions for ways in which MH-CoPES may overcome some of the barriers identified, and assist in making evaluation trustworthy and useful. These suggestions are presented in Table 7

High consumer involvement in implementation.

Establish an independent, consumer- directed organisation to take responsibility for collecting and analysing data. Participants stated that consumer ownership will be important in developing trust, and will assist in overcoming fear of repercussions and the other barriers summarised above.

Provide feedback about the results (that is, open reporting and wide dissemination of results). Receiving feedback will demonstrate the usefulness and trustworthiness of the process.

Evidence of service change, which it was acknowledged will take time. If results are not seen (that is, changes in the ways services are delivered) it was suggested that the majority of consumers will not view the process as trustworthy and useful. Participants in consultation recognised that building this level of 'trust' will be difficult because there is a lot of 'bad press' to overcome in the mental health services/area broadly.

Table 7.

Summary of suggestions from consultations regarding how barriers identified may be overcome and the structures to support consumer evaluation in NSW mental health services

High consumer involvement in implementation – consumer-directed
Independent consumer-directed organisation established – maintain ownership of data collection, analyses and reporting. Assist in overcoming fear of repercussions, limited in-service resources of time
Open reporting and wide dissemination of results – establish trustworthiness of the process
Evidence of service change over time
Involvement of local consumer groups to collect information about consumer perceptions and experiences of mental health services
Involvement of service partners like GPs and NGOs as collection points for consumers to drop-off/return completed questionnaires
Involvement of service partners like NGOs to assist in informing consumers about MH-CoPES, and in supporting consumers to complete questionnaires if needed
Make use of computer and internet technology, to provide alternative methods of giving feedback
Questionnaires and interviews remain short
Build access to appropriate support in to the framework
Establish an option that is verbal for providing feedback, and involve talking with another/other consumer/s
Create a flexible process, which can be adapted to different service needs, while also providing consistency across the state
Develop strong education and information campaigns to inform: a) consumers, and b) staff and services
Involve consumers in MH-CoPES on the ground
Capture service strengths, and build on the positive aspects of services, as well as identify areas that need improvement

Make use of local consumer groups to collect information about consumers' perceptions and experiences of mental health services, suggesting that many consumers may be willing to provide their feedback in this forum who would be unlikely to take part individually.

Involve service partners, like GPs and NGOs, as collection points for consumers to drop off/return completed questionnaires. It was suggested that while providing postage paid return envelopes would prove helpful, doubt was expressed regarding the return rate this would achieve. Therefore, a range of options for return was encouraged.

Use service partners like NGOs to assist in informing consumers about MH-CoPES. It was further suggested that some of these organisations could provide support to consumers in completing written questionnaires if consumers require assistance.

Make use of computer and internet technology, to provide alternative methods of giving feedback. Existing technology, and new technology could be explored, to develop methods for consumers to give their feedback about services.

Questionnaires and interviews remain short. No unanimous concept of appropriate length for questionnaires was determined, although generally a single page was suggested as about right for written methods of collecting information. For many participants in consultation this posed a tension – between the possibilities of having an opportunity to discuss a wide range of issues that are important, versus realistic time frames to commit to.

Build access to appropriate support in to the Framework, as support will be necessary for some consumers. For example, a flexible system should include the option to nominate a carer to assist consumers in providing their feedback.

Employ consumer interviewers. Consumers who participated in consultation suggested that in cases where a consumer chooses to provide their feedback verbally, having consumer interviewers helps create a sense of safety, and assists consumers to feel understood. Participants suggested that this option would encourage many consumers to take part in evaluating the services, who, otherwise, may not get involved. They suggested that this may also assist in services hearing views that would not otherwise be accessed.

Create a flexible process, which can be adapted to different service needs, while also providing consistency across NSW. It was suggested that this will assist in creating a process that is useful and appropriate in the different parts of the state (rural as well as metropolitan). A process with many tools that could be utilised was suggested to be part of an adequate level of flexibility.

Develop and implement strong education and information campaigns to inform: a) consumers, and b) staff and services. These campaigns are essential to ensure that a clear understanding is developed by all stakeholders about the reasons for consumer evaluation, the importance of consumer evaluation, consumers' rights to active evaluation, consumer and service responsibilities in evaluation, and the overall process of MH-CoPES.

Involve consumer consultants in MH-CoPES "on the ground". Participants acknowledged, however, that this would need to be viewed as new work, negotiated and fully resourced in addition to the roles consumer consultants already play. Having consumer consultants involved appeared to reduce the sense of risk to privacy and confidentiality for consumers, as they argued that consultants would need access to service databases to contact consumers to take part in MH-CoPES. Participants suggested that having consumer consultants act within services as MH-CoPES agents could then, improve return rates because this would allow an opportunity for follow up with consumers. This in turn would assist in satisfying services' needs for reliable and valid information.

Consultants playing a pivotal role, however, also creates a particular tension; consultants are a key part of the mental health services that consumers would be asked to evaluate. The counter argument is that consumers, who are not consultants, but trained in the skills necessary to carry out the data collection and follow up work, be situated within services but work for an independent organisation.

Use the tools and process to capture service strengths, and build on the positive aspects of services, as well as to identify areas that need improvement.

2.8.2 Phase 2 consultations

Feedback from participants in Phase 2 consultations reiterated many of the arguments participants presented in

Stage 1 consultation. These forums were held during early 2005 in Rozelle, Liverpool, Penrith and Newcastle.

Participants in these consultations stressed the importance of "top down", and "bottom up" support. They spoke of the need for strong support, for example, from the Centre for Mental Health, and Area Mental Health Directors, as well as from staff on the ground.

1. Frequency of the evaluation cycle

Broadly, participants involved with consultations recommended that a cycle of evaluation occur regularly, taking between three and 12 months to complete.

Some participants suggested that a yearly cycle may fit best with current service improvement processes.

Some participants suggested a census method as an alternative to continuing cycles. Twice yearly, all consumers who have contact in a two week period could be approached for their feedback.

Others suggested a six monthly evaluation cycle more appropriate for continuing improvement.

2. Data collection

Participants reinforced that the questionnaire cannot just be handed out with the expectation that consumers will complete and return it. People will need to "sit down" with consumers and discuss it with them.

Consumers should be trained to assist in administering questionnaires, and facilitating other methods (eg: focus groups) for feedback.

3. The tools

Participants made the following suggestions about the tools needed to assist in collecting consumers' feedback about services.

Tools need to be useful for change: answers need to reflect concrete actionable issues.

Verbal feedback options (focus group/interview methods) need to be available.

Two versions of the inpatient questionnaire could be helpful. One very short, which could be completed at discharge, and a second longer version, which can be completed and returned later.

4. Reporting of feedback

Timeliness will be key – a quick turn around from analysis to reporting. Suggestion of approximately six weeks from the data cut off would be necessary to keep some staff engaged.

Feedback needs to be specific to local mental health programs, rather than too global (eg: only area level information), otherwise participants identified the risk that staff and management of smaller local teams will not see the relevance or need to take responsibility for issues raised, rather will see this as another services' problem.

Needs to be available at all levels: to areas, staff and consumers.

Reports should make clear, concrete recommendations for action, based on the data. If too conceptual, these recommendations will be open to multiple interpretations, and thus may become redundant.

Reports should, in making recommendations, highlight a range of goals: shortterm achievements and long-term goals. Short-term goals will be important to assist momentum, and allow people to see achievements.

Feedback and reports to areas need to be produced in a language that services know and use – although the question of whether this discounts consumers' language was also raised.

5. Action and change

High consumer involvement in determining what and how change needs to occur based on the data collected is necessary.

Needs to involve staff and consumers talking together about the feedback from reports, and determining action together. This should be done via formal meetings to address feedback, as part of a services' agenda.

Consumer workers, consumer networks and groups

need to be part of the action and change process, and decision making.

Use a range of dialogue and focus group methods to gather more in depth information, where needed, about problems highlighted in reports. These groups can also be part of shaping directions/details for changes.

6. Structures and leadership for MH-CoPES

At all consultations, the issue of long-term commitment from Government was raised as essential.

Participants indicated that Area Mental Health Directors need to provide support through leadership, interest in the findings, and funding.

Participants raised the concept of making MH-CoPES a mandatory process for services – through performance agreements. Participants stressed that collecting the data is only part of what needs to be mandatory, suggesting that services should also be tied to acting on the feedback appropriately.

Participants suggested that to assist in making all services' staff accountable engaging with MH-CoPES could be built into staff job descriptions and performance appraisals.

Comparisons of AHS, mental health services' performances across the state to assist as an incentive to change.

Sustained support to implement changes will be necessary.

7. Other issues raised in Phase 2 consultations

Culture change: will need major support.

Many recommendations are likely to relate to the need for education around issues raised by the feedback. It will be important that educators in services have a strong consumer perspective, and involve consumers in staff training, to ensure a consumer perspective is embedded in training.

State wide consistency needs to be developed relating to consumer consultants employed, as well as consumer participation initiatives and opportunities more broadly. Currently, participants in consultation suggested that there are inequities across the state.

Work needs to go into working with staff to build their understanding that this is not a process designed to attack them and their work, but to assist the work they do, and make it easier/better for all stakeholders. Careful thought about how to reduce any threat staff may feel will need to be given (for example, how will it assist clinical practice? what are the benefits for clinicians?).

The lessons learned and changes made by consumers' feedback should be used to change staff training at formal/university level, so that new staff have this built in as part of their role.

Clear responsibility within services needs to be established for consumer evaluation through dedicated, funded roles. This will also demonstrate clear responsibility from high level management to respond to consumers' feedback. Teams to manage and monitor consumer evaluation within services need to comprise consumer and non-consumer employees plus management. One aspect of this job would include ensuring reports and feedback are brought to people's attention, and remain on the Director's agenda.

SECTION 3

The principles underpinning MH-CoPES

Nine interconnected principles underpin the evaluation of mental health services by consumers, and thus MH-CoPES. These principles are summarised in Table 8 below.

Table 8.

Principles underpinning MH-CoPES consumer evaluation

Recovery Orientation	A recovery orientation to service provision means that at a systems level mental health services are to be guided by consumers' experiences and views of what works and what does not. Consumer evaluation of services is a central feature of a recovery orientation.
Consumer participation	Consumer evaluation of mental health services is an enactment of genuine consumer participation, most particularly at service and systems levels.
Empowerment	Consumer evaluation of mental health services is fundamentally informed by, and directed towards creating opportunities for consumer empowerment.
Accountability	Services are accountable to consumers, families and carers, staff, funding bodies, and the NSW community.
Continuous improvement	Services should be striving to develop and advance their service delivery as a core part of their work. Continuous improvement is one of the quality indicators of NSW Health.
Privacy and safety	Evaluation of mental health services should be an activity that consumers and staff engage in knowing their individual privacy will be maintained without fear of adverse repercussions.
Accessible and equitable	Evaluation processes should be freely available to everyone wishing to become involved.
Efficient and effective	The process of consumer evaluation should be easy to engage in, without creating unnecessary extra burden for consumers, staff or services. The process should also be effective, in that it guides service change on the ground.
Service and systems focus	The primary focus of consumer evaluation of services is to identify problems within the system, and at service levels. It is not aimed at identifying problems at individual levels, which is the focus of other quality processes in services.

These principles are discussed in greater depth below.

Recovery Orientation

Recovery from mental illness has been defined 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. Recovery involves the development of new meaning and purpose in one's life..." (p. 15).[11] The TWG view a recovery orientation as the most appropriate approach services can take in supporting consumers.

The basic assumptions of a recovery-focused mental health system involve the following beliefs:

- consumers hold the key to recovery, not professionals;
- professionals may provide support to consumers, however, recovery is just as possible without professional intervention;
- good, human, relationships are one important facet of the recovery process;
- recovery is not a linear process;
- recovery is also about consequences of the illness, not only symptoms; and
- the concept recovery is not synonymous with a finite, 'no symptoms' type of state, which means recovery can occur even if symptoms reoccur.[11, 12]

Davidson et al[118] highlight the impact that opportunities to contribute to community have in recovery for many consumers.

Recovery involves consumers assuming responsibility for their lives by making choices and learning from that process; for services this means that mental health workers must affirm and nurture the process of consumer choice. MH-CoPES is one important facet of consumer perspectives being 'built in' to service planning and change in NSW services. The TWG see consumer evaluation of services, and collaborative partnerships in service improvement, as firmly embedded in a recovery orientation.

Evaluation of services, grounded in a recovery orientation, inherently becomes consumer-directed. A recovery focus means that consumers' views and perspectives are essential to developing better, more meaningful mental heath services. Historically, it has been demonstrated that consumer definitions of quality and the health service definitions of quality do not match[119.] When services are based in a recovery orientation, as described by the assumptions above, services essentially need to be open to the assistance of consumers in their development; that is, consumers identifying the service gaps, weaknesses and strengths, and guiding future development and change. Consumer evaluation of services importantly recognises the contribution consumers make to improving service provision.

Consumer participation

The principle of consumer participation links to Chamberlin's[120] discussion of citizenship and rights. Citizenship is enacted through participation in MH-CoPES. Consumer participation has been increasingly recognised internationally as fundamental to good mental health services over recent decades, strongly influenced by the consumer movement. Consumer participation is recognised as important at different levels, for example, the individual treatment level, service level, and systems level.

As a principle underpinning MH-CoPES, participation at all levels is important, although the focus is participation at the service and system levels. MH-CoPES is fundamentally about consumer participation in evaluation of local mental health services in NSW, and is an important form of building in recognised mechanisms for consumers to have a voice in service development, planning, and improvement. Consumer participation at systems levels drives MH-CoPES in terms of developing state wide processes and data collection – and the ownership and management of MH-CoPES is a systemically important area where consumer participation is vital.

Genuine consumer participation in mental health services means that partnerships between consumers and mental

health workers develop, working together to achieve the type of services needed. This type of collaboration is based on respect and equality, and recognition of the important qualities both consumers and mental health workers contribute to all aspects of the service.

Empowerment

While empowerment means different things to different people, the MH-CoPES TWG sees empowerment as a social process that can occur at different levels (eg: individual, group and community levels), and essentially aims to help people gain control over their own lives. Nelson et al[53] define empowerment as: "opportunities for and conditions that promote choice and control, community integration and valued resources" (p. 127).

MH-CoPES is about the power of the consumer voice. From the TWG's perspective, it is important that the concept of power is not viewed as "all or nothing". Genuine consumer participation as an underpinning principle of evaluation of mental health services is essential because it builds a forum where consumers have real input to determining what services look like over time.

Empowerment guides the overall attitude and approach to developing mechanisms that enable consumers' genuine input to evaluation of services. Empowerment as a principle means that not only does the opportunity need to be available to consumers to comment on the effectiveness of services, but also, that services need to take responsibility for listening to and actually hearing consumers' voices in this context. The next step is action in partnership – empowerment means that consumers' voices and views should make a difference to how services operate and develop, and consumers and services should determine these changes collaboratively. Underpinning this, MH-CoPES is about creating ongoing relationships and dialogue between everyone involved in services (consumers and staff, staff and management, consumers and consumers) – fundamentally changing the environment to foster greater empowerment for consumers, for staff and for services. The TWG see this as an opportunity for both individuals, and local communities to become empowered.

Accountability

Being accountable involves services taking responsibility and being answerable to consumers. Accountability means being able to describe and explain what is occurring both in services, and as part of the evaluation of services. These concepts apply at individual levels (ie. staff and consumers); local service levels, area levels and the state level, in terms of funders and the broader community. Accountability means all stakeholders sharing responsibility and genuinely investing in consumer evaluation of services as a continuous improvement mechanism. Developing a state wide, consistent approach to consumer evaluation of mental health services is also part of enacting accountability. This will assist services to be answerable at local levels to consumers and the community more broadly, as well, answerable at the state level through state wide reporting and comparisons.

Accountability as a principle of MH-CoPES relates to both services and consumers. For services, MH-CoPES is about accountability at the most fundamental level – being accountable to the consumers who use the services. By genuine consumer involvement in evaluating services this type of accountability is further developed. Services need to ensure that the MH-CoPES process is available, that feedback is used, and that in partnership with consumers, actions are determined and taken to change services, based on the evaluation feedback.

Accountability also relates to consumers. Partnership is a two way process, and consumers have responsibility for engaging in partnership with services, to give feedback and help services change. Without accountability on the part of both services and consumers, MH-CoPES will not succeed.

Continuous improvement

Continuous improvement is the process of ongoing, systematic refinement of a service – continually working towards creating a better service. The notion of continuous improvement recognises that there are goals, standards, and ideals to strive towards, but also that there is a need

for ongoing effort. Standards are always shifting, and ideas of what is ideal are bound in time and place, and thus are continually developing. Thus, continuous improvement is an activity that never stops; expectations of services will always be changing.

MH-CoPES is fundamentally about working to identify areas in services that need improvement, as judged by consumers, as well as identifying what already works effectively, and building on these strengths. Regular review and evaluation is an integral part of continuous improvement work in services, and MH-CoPES tools and processes give information and guidance to support continuous improvement in mental health services.

Given that this is an underpinning principle, the TWG see improvement as part of the core work of services, and that consumers play a central role in this improvement. The MH-CoPES process has been strongly influenced by the literature on enacting continuous improvement. Furthermore MH-CoPES tools and processes themselves also need to be open to continual improvement as they are used and implemented over time.

Privacy and safety

In the process of enabling consumers to genuinely take part in evaluating the services they use, issues of individual privacy and rights to anonymity must be maintained. This principle has implications for how data are reported and used. The term "individual" includes not only consumers, but also staff members, and extends to services. Consumers must be able to evaluate the services honestly, without fear of retribution – this process should be psychologically safe for all involved. Issues of privacy for staff need not preclude serious complaints about individual staff members being dealt with, but privacy should be maintained in an appropriate response to any specific issue raised through MH-CoPES data collection.

While individual privacy is essential, it is important to consider the implications of accountability and transparency in conjunction with this principle. The TWG acknowledge that privacy can be a serious concern in terms of reporting for smaller services, however, this principle should not be used by services to hamper either accountability at any level (local or state), or transparency of the process.

Accessible and equitable

Opportunities to take part in consumer evaluation of mental health services need to be easily available and equitable; that is, everyone who uses a mental health service should have the same level of opportunity to give their feedback. Each persons' view is valid and worth hearing. Equity involves ensuring specific needs are met for different individuals. This relates to issues of age (appropriate tools and mechanisms need to be available for people at all stages of the lifespan), culture (in its broadest sense, inclusive of, but not limited to, nationality issues), as well as dis/ability. Flexibility and breadth of ways to be involved must be built in to the processes, and services must work to implement MH-CoPES ensuring easy accessibility. Accessibility relates not only to the overall evaluation process, but also to individual components of the process, including data collection, reporting and action phases. Each stage of the process, and the results from each stage, must be accessible to all.

Efficient and effective

Efficiency has an economic implication in terms of achieving value for the money spent, or gaining maximum benefit from resources expended. Efficiency is also about the burden placed on everyone involved; this needs to be minimal, or at least viewed as worth the results gained by those involved. The process also needs to be effective, in terms of achieving the goal to which it aims to achieve; that is, guiding change within mental health services, locally and at a state wide level.

System and service focus

MH-CoPES is one mechanism within the quality processes of NSW mental health services. The primary focus of consumer evaluation of services is to identify problems within the system, and at service levels. It is not aimed at identifying problems at individual levels, which is the focus of other quality processes in services.

SECTION 4

The MH-CoPES framework for consumer evaluation of mental health services

One of the key objectives for Stage 1 of the MH-CoPES project was to consider the overall processes necessary for consumer evaluation of mental health services in NSW. A key focus from the project's inception was to ensure that consideration was given not just to how to collect or measure consumers' views of the services, but that clear attention is paid to understanding how this information would then be used to improve, and develop, local services. The review of relevant literature conducted by the TWG supported the view,[119] that measuring consumer perceptions and experiences of service quality and delivery was only one part of a complete framework necessary for this to make real changes to services.

The Framework will be a guide for NSW Mental Health Services to conduct full consumer evaluation of their services.

The Framework will guide a consistent approach to consumer participation in evaluating the services across all public MHS in NSW and ensure that this is placed within a continuous service improvement context.

The Framework outlines the steps and processes involved in conducting a full cycle of evaluation.

The Framework presented here is one of the primary products of Stage 1 of MH-CoPES. The first stage of the project has been development; therefore, the next step will be to trial the Framework within local mental health services in order to continue its development. This continued development will need to explore the alternatives and options involved at each step of the evaluation cycle, and produce a clear understanding of the resource and funding implications of implementing the Framework.

While a number of international and local examples were identified in the review, most were stand alone 'tools'. Limited examples of 'frameworks', that consider the broader issues of full evaluation processes were found. The Understanding and Involvement project conducted in the mid to late 1990s in Victoria,[26] the Consumer Evaluation of Mental Health Services (CEO-MHS) project conducted between 2001 and 2004 in NSW[121] and the User-Focused Monitoring project in the UK[103] are some of the few examples identified where more than a survey or questionnaire had been considered as necessary, and broader frameworks of evaluation were developed or adopted. The MHSIP work conducted within the United States is an important example of a consumer-oriented performance monitoring system, where a key source of information is their consumer survey.[35, 122] The MHSIP has considered issues such as involving peer-to-peer surveyors in making consumer evaluation accessible and genuine. In most states using the MHSIP framework, consumers taking part can choose how to provide their feedback from a number of options. Using the examples of existing frameworks, and continuous improvement and evaluation models, plus feedback from consultations, the MH-CoPES Framework was developed. The MH-CoPES Framework for Consumer Evaluation of Mental Health Services is presented in Figure 2. This diagram shows the overall process of consumer evaluation recommended. The Framework consists of four phases:

1. Data collection;
2. Data analysis;
3. Reporting and feedback; and
4. Action and change.

Multiple issues need to be considered at each of these phases. These are discussed in the section 4.1.

The MH-CoPES evaluation cycle is based on the principles of consumer evaluation articulated earlier in this report. A number of specific recommendations also underpin the Framework. These are that:

The evaluation cycle occur on a regular basis. Agreement on regularity within constraints of the day-to-day management of services needs to be fully scoped as part of Stage 2.

"ultimately, it is at the level of people communicating with each other that human values have the greatest potential for becoming incorporated into the institutions of society"[1]

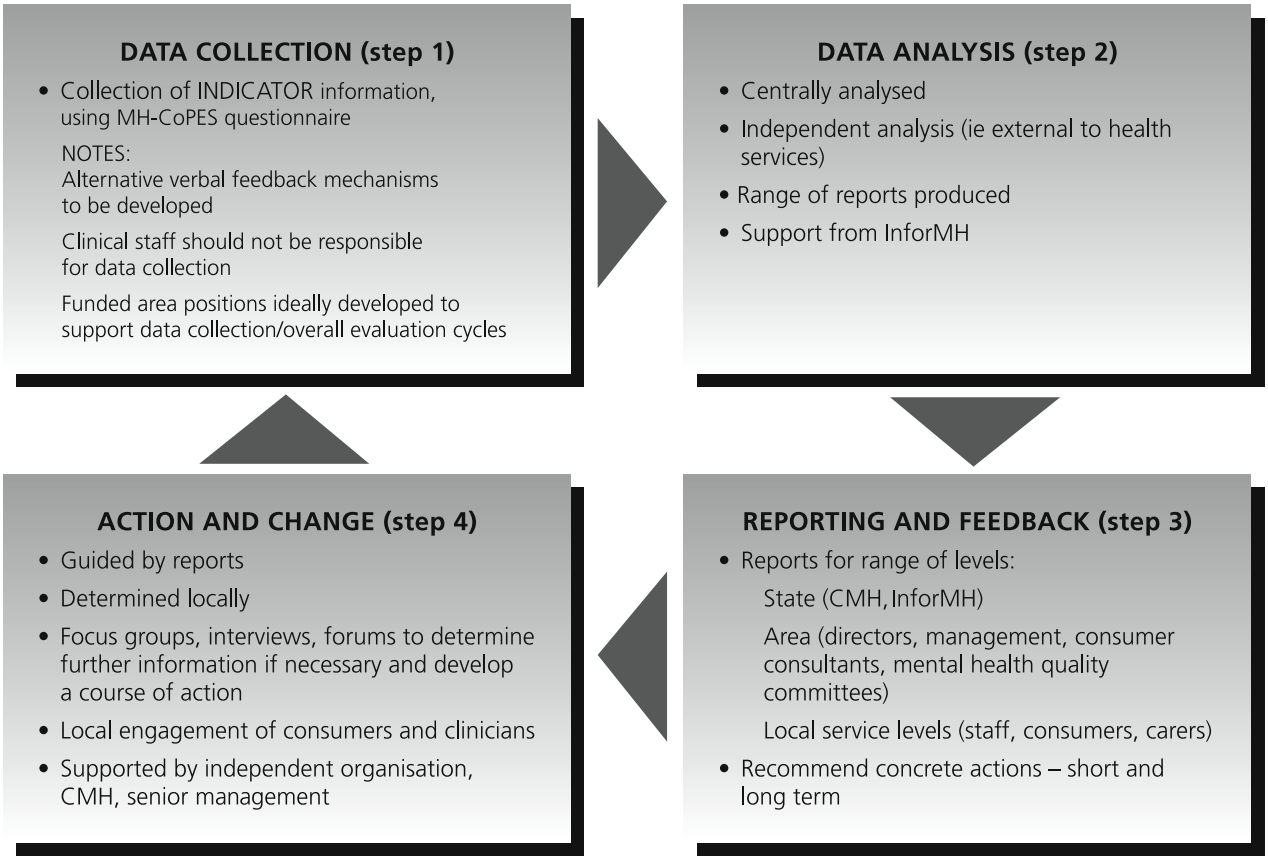

Figure 2. A 4-step model of MH-CoPES Consumer Evaluation of Mental Health Services recommended. Funding and resource implications and the viability of the model need to be fully analysed in Stage 2 of MH-CoPES

All consumers using public mental health services have the opportunity to give feedback regarding their experiences and perceptions of services, through MH-CoPES evaluation.

Evaluation cycles be managed and engaged in partnership by:

An independent consumer-directed organisation;

Consumers and staff in local services; and

The Centre for Mental Health, NSW Department of Health

Dedicated positions within AHS, mental health services are developed to support local leadership and develop a clear line of responsibility for engaging in the MH-CoPES evaluation process;

Engaging in the full cycle of evaluation is built into performance agreements between NSW Health and Area Mental Health Service Directors.

Genuine choice is available to consumers in how to take part and how to give their feedback.

Ideally, clinical staff involved in a consumers' treatment and care play no direct role in the process of administration, filling in, or return of questionnaires.

Confidentiality be a priority consideration throughout the process of consumer evaluation. Issues of privacy/ confidentiality are essential to building in safety for consumers taking part, and legislation regulating privacy in NSW – the Health Records and Information Privacy Act 2002, and the Privacy and Personal Information Protection Act 1998 – must be complied with.

4.1 The phases of MH-CoPES consumer evaluation of mental health services

4.1.1 Data collection

The focus of this phase of the evaluation cycle is on providing opportunities for consumers to report on their experiences with, and perceptions of, the services they have received in the last six months. The data collection phase of the evaluation cycle will produce indicators of service strengths and areas needing improvement from consumers' perspectives.

During this phase of the evaluation cycle consumers will complete the MH-CoPES Questionnaires, and ideally, in the future, other tools will be available which consumers can use to provide their feedback to services.

A continuous flow of data collection is recommended. While data collection should occur continually, discrete cut off points will be established, determining when data analysis for reporting and feedback will occur. Therefore, it is envisaged that if a regular quarterly cycle of evaluation is adopted, four cut off points would be determined throughout the year. All data received during the period from the previous cut off and current cut off date would then be included in analyses for that period.

The following recommendations are made for the data collection phase:

1. Administration.

It is recommended that consumers have an opportunity to provide their feedback:

- about each inpatient experience. It is recommended that the most appropriate time for consumers to provide feedback about inpatient experiences may be shortly after discharge, however, advice in consultations indicated that if a consumer is in hospital for longer than a week, the choice to provide their feedback while still in hospital should also be available.
- on a regular six monthly basis while using community mental health services.

Due to privacy concerns, ideally, clinical staff should not be involved in distributing, collecting or return of consumers' feedback. A preferred option, highlighted in consultations, is that consumers are employed to administer the MH-CoPES data collection. A further option that staff who are not directly involved in clinical care be involved in some aspects of data collection. Administration may include group information sessions, where consumers are introduced to the MH-CoPES process and tools, and provided with questionnaires to complete in their own time; or administration may involve administering the Questionnaire verbally, and recording a consumer's responses, in person, or via a telephone.

Administration should be personalised. Learning from MHOAT data collection, and the experiences of consumers and service providers relating to use of the self report measure, introducing the MH-CoPES tools and process to consumers will be an important part of ensuring the success of MH-CoPES consumer evaluation of mental health services.

Alternative administration options need to be explored and developed. This includes alternatives for individuals – for example, online completion of questionnaires and interview approaches. As well, consumers in consultation strongly advocated for group alternatives, such as focus groups, which they suggested could usefully link to existing consumer groups.

2. Support.

Appropriate individual support mechanisms need to be available locally for consumers who wish to engage in evaluating the services they use, but who may need assistance in providing feedback. In consultation a number of support options were suggested, including establishing a free-call telephone line for help; trained consumer support workers to assist when required, which need to be appropriately funded local positions. In addition to these formal mechanisms, it was also suggested that clear information be provided stating

that help can be sought from trusted family or friends if a consumer wishes.

Area-level support will also need to be evident during the data collection phase of the evaluation cycle. Attitudes of service staff and management should be supportive of the concept of consumer evaluation. Support at this level should also occur through commitment of resources to ensuring that opportunities for consumers to participate in evaluation are available.

Education initiatives for consumers and staff should be developed and implemented to support understanding of the process of MH-CoPES consumer evaluation, and to support consumer participation in the data collection phase.

3. Maximising response rates.

Achieving high response rates will be important in regards to how the information gathered is viewed publicly, and how seriously it is taken by services and funding bodies. Achieving adequate response rates is a challenge that needs further consideration for MH-CoPES.[123] Ensuring appropriate and safe opportunities to give feedback, with clear information about the process of evaluation so consumers can make an informed choice about their participation appear to be essential to achieving adequate response rates.

The barriers highlighted in consultation raise a number of important considerations, such as opportunities for verbal responses and personal support. The example of the MHSIP consumer survey in the United States demonstrates that of all the administration methods used, face-to-face and telephone administration methods achieved the highest response rates.[124]

Literature discussing response rates in questionnaires or surveys suggests that follow up of non respondents (eg: mail reminders, telephone and personal follow ups) is the most effective way of achieving good response rates.[115, 116, 117] However, creating a process that allows for follow up has both real and perceived effects on anonymity, and therefore safety in participating. If it is not known who has returned a questionnaire and who has not, reminders cannot be targeted only to non respondents. Either all consumers could be reminded, with an apology if they have already completed and returned a questionnaire, which is a time consuming and costly option; or no reminders could be given, which will cost in terms of lower response rates.

For MH-CoPES, it appears that efforts to achieve adequate response rates need to be focused around developing adequate flexibility in how consumers can provide their feedback, alternative choices for administration method, a supportive environment, clear options for personal support if required, and personalised, accessible information and education about MH-CoPES to both consumers and service staff.

4. Return of feedback.

Consumer information should not be returned directly to the mental health services, but should be returned to an organisation independent of the mental health services where it will be aggregated, and incorporated into feedback for the service.

A number of ways consumers can return their feedback should be made available, and may include reply-paid envelopes being distributed with questionnaires and safe and confidential return boxes in appropriate settings managed by the independent organisation.

4.1.2 **Data analysis**

This phase of the evaluation cycle is primarily focused on collating and aggregating the information consumers provide about their perceptions and experiences of mental health services. The purpose of these analyses is to turn the information provided by individual consumers into meaningful group information that can be used by AHS, mental health services and consumers to plan and improve services.

The following recommendations are made regarding the data analysis phase of the evaluation cycle:

Data analysis should be managed and conducted by an independent, consumer-directed organisation. This was seen as important for a number of reasons:

- for consumers to be ensured of the safety of the process completed questionnaires or other forms of data will go directly to an independent, external organisation. This will assist in ensuring confidentiality and anonymity;
- to ensure the burden on services is not increased by this initiative;
- as the word 'independent' implies, to ensure the objectivity and transparency necessary in analysing and reporting this type of data; and
- a consumer perspective was viewed as essential to the data analysis and interpretation process, a view supported by others in the field.[125]

Careful consideration should be given to issues of data management and storage to ensure confidentiality. Personal identifiers, such as names will not be sought as part of the data collection process, so data held by the independent organisation will remain anonymous.

The data analysis phase should produce a range of reports, for:

- consumers, and consumer networks;
- AHS, mental health services;
- the Centre for Mental Health, NSW Department of Health;
- other government departments, and sections of the NSW Department of Health;
- service partners, for example, NGOs and GPs; and
- carers and carer networks.

The reports produced should state clear, concrete and actionable recommendations, with short and long term goals considered.

Support for the initial implementation of this phase of the evaluation process should be sought from InforMH. After initial set up it is anticipated that an ongoing partnership between the Independent Consumer-Directed Organisation and InforMH would follow.

4.1.3 **Reporting and feedback**

The purpose of the reporting and feedback phase of the evaluation cycle is to ensure the information received from consumers is heard, primarily by AHS, mental health services. Reporting and feedback to the range of stakeholders involved in mental health services, however, also needs to be considered. Consumers and the Centre for Mental Health are two other primary stakeholders. Participants in consultation suggested that three levels of reports should be produced:

- state level, which would include reporting to the Centre for Mental Health, NSW Health, and other state organisations, like InforMH and the Official Visitors Program;
- AHS, mental health service level, targeted to all the people involved at Area levels including Consumer Networks, and Consumer Consultants, Mental Health Directors and Management, Quality Committees; and
- local service levels, again targeted at all of the people involved, for example, consumers, service staff and managers.

The content of the reports will be constituted from the aggregated information collected at Phase 1, analysed at Phase 2.

The TWG recommends that the content and structure of reporting is explored in greater detail with stakeholders, to develop clear protocols, as part of the second stage of the MH-CoPES project. It has been recommended, however, that the reports should provide clear, direct and concrete recommendations regarding areas that require change, based on the information provided by consumers. Short term and long term goals, related to these changes, have also been suggested as useful content for the reports.

"Interviews or focus group methods are especially helpful in assessing user views of services and healthcare provision and in revealing why some care is perceived as poor quality"[126]

The reports will provide a means to develop cross-Area understanding of the strengths in mental health services around NSW, and sharing of expertise and knowledge. It is suggested that to aid this type of use, comparisons of AHS, mental health services' performance on MH-CoPES are produced and reported to Area Mental Health Directors.

4.1.4 **Action and change**

The action and change phase of the evaluation cycle is about consumers and services engaging together at a local level to act on the findings from Phases 1, 2 and 3; creating better services and better outcomes.

It is recommended that during the action and change phase of the evaluation cycle consumers and services, working in partnership, should:

develop greater understanding of the issues raised in MH-CoPES reports, if necessary through formal and informal dialogue. Formal dialogue may include facilitation of focus groups to follow up and clarify key areas needing improvement;

determine local priorities for change, using the MH-CoPES feedback, and again, augmented by local discussion and formal processes such as focus groups or community forums, run to prioritise actions;

develop action plans to address key issues raised.

implement the action plan; and

report back to a central body, either the Centre for Mental Health and/or the Independent Consumer-Directed Organisation on the action plan and change initiatives.

As with the Data Collection Phase of the process, appropriate support for the Action and Change Phase was emphasised as essential, by participants in consultation. Types of support stressed as essential were:

clear guidance and mandate by the Centre for Mental Health, NSW Department of Health, supporting MH-CoPES consumer evaluation as a full quality improvement cycle. That is, clear expectations that the information consumers' provide will be acted upon, in partnership;

adequate and sustained funding, when available, from the NSW Department of Health to implement changes identified as required;

clear leadership from Area Mental Health Directors demonstrated by a commitment to participation and partnership and consumer perspectives, interest in the reports received and prioritising of issues raised, and allocation of necessary funding;

dedicated roles within the service, which establish a clear line of responsibility and management for the overall process, including support of the action and change phase; and

expertise and advice from the Independent Consumer-Directed Organisation, for example, to assist in building greater depth of understanding of the issues raised, or to provide independent facilitation of focus groups if required.

SECTION 5

The MH-CoPES questionnaire: tools to assist consumer evaluation of mental health services in NSW

Two versions of a Questionnaire, one for use by people in current/recent contact with inpatient mental health services, and the other for people in current contact with community mental health services have been developed as part of Stage 1 of the MH-CoPES project.

The Questionnaire is one tool available to assist in the data collection step of the evaluation cycle. The questionnaire needs to be trialled in context next, to finish it's development.

The Questionnaires presented here were developed to be one option that consumers and services can utilise to assist in the process of consumer evaluation of the mental health services. While in Stage 1 of the MH-CoPES project, it was agreed that the focus would be to develop two versions of a Questionnaire, additional tools will be necessary, and need to be developed. This was a clear message received throughout our state wide consultation. These Questionnaires, therefore, are not viewed as the "whole toolkit" needed.

The Questionnaires were developed to:

- be used during the data collection phase of the MH-CoPES evaluation cycle;
- assist consumers in providing feedback to the mental heath services they use; and
- assist mental health services to hear consumers' feedback.

The TWG recommends that the information gathered through the Questionnaires, if used as part of the MH-CoPES evaluation cycle, is analysed by an Independent consumer-directed organisation, to guide recommendations reported back to mental health services. The information will:

- act as an indicator of areas of strength and areas requiring change, based on consumer experiences and perceptions of the services;
- be group data, not individual clinically relevant data, although consumers' are free to discuss their responses with service providers; and
- contribute to cycles of quality improvement, through triggering following phases of analyses, feedback, action and change (see the MH-CoPES evaluation cycle) and by contributing to existing quality information.

The Questionnaires were developed from a series of consultations and informed by the literature reviewed, as described in section 2. After seven consultation forums (stage 1 consultations) the TWG produced a first draft of the Questionnaire. Items were selected from the list of 88 preferred items identified in stage 1 consultations to limit overlap of issues and ensure coverage of domains identified as relevant to consumers. Coverage of domains identified in the original project brief, of: availability of services; access to services; getting information; treatment and assistance; staff, consumer relationship; and participation were also taken into account by the TWG. Consideration was also given to the ability of items to be used to indicate areas needing improvement. This meant the TWG considered what avenues for change answers to specific items suggested. Feedback about this first draft was then received through stage 2 consultations, and the state wide workshop held in April 2005. Using the feedback obtained, the TWG produced the versions of the Questionnaire presented here. Items were adapted to fit the three-point improvement scale developed. The scale was developed to be active, with consumers providing judgements about their experiences with services, rather than simply being asked to agree or disagree. A three-point scale was chosen by the TWG because:

- the TWG agreed, based on the feedback from consultations, that inviting consumers to judge aspects of service delivery, using three choices would provide a meaningful opportunity for judgement, without asking for a level of discrimination that may become meaningless;
- in interpretation and presentation of results, many five-point scales adopted are collapsed and reported as

three-point responses. So, categories such as "strongly agree" and "agree" and likewise, the opposite end of the scale "strongly disagree" and "disagree" are frequently collapsed and reported together. The TWG wanted to ensure that consumers' direct judgements would be maintained in data reporting.

Trialling and piloting of these tools needs to occur as the next stage of development. This will establish the Questionnaire's use in practice, and complete their development before implementation. Therefore, some of the phrasing included in the Questionnaires (particularly the introduction) is currently based on information known at the time of compiling this report, and is appropriate for piloting. Further development, based on the feedback received during piloting and on developments to the MH-CoPES Framework made during Stage 2 of MH-CoPES, will be required to prepare the Questionnaire's phrasing for routine use in mental health services.

MH-CoPES questionnaire for people using community services

Your opinion will help create better services and better outcomes: this is your opportunity to help services improve in the North Coast Area Health Service.

This questionnaire will gather your views about the community mental health service you have used in the last six months. *Filling in this questionnaire is voluntary.*

Privacy guarantee:
If you choose to complete the questionnaire, NSW Health guarantees that your privacy will be maintained.

- Your completed questionnaire will go to an organisation independent of the health service – your community mental health service will not see your completed questionnaire.
- No names will be used on the questionnaires.
- Reports will not identify individuals in any way.

How will the information I give be used to improve services?

- Every Area Mental Health Service will receive a summary report showing all the things people have said need improvement.
- Each service is then expected to work with consumers to make improvements based on the summary report.
- Summaries of the information will be publicly reported.

How do I fill it in?

- You will be asked to say what needs to be improved, from YOUR OWN EXPERIENCE.
- To answer most of the questions, just choose the coloured circle that is the best answer for you:
  - The red circle means *this needs major improvement*
  - The yellow circle means *this needs some improvement*
  - The green circle means *this needs no improvement*

For example, Q1 says:
The ease of getting the services and supports I need … 

If you feel this was something that needed some improvement, you would mark the yellow circle with a cross, like this: 

To return the questionnaire

- Please do not give it to back to the service
- Put it in the return envelope included and return by mail.

If you want help to fill in the questionnaire you could: (options to come later)

If you want your opinions to be included in a summary report to the specific service you used, please complete this section. If you only want your opinion to be included in the summary for the whole Area, please go to Q1.

- How long have you been using mental health services? Tick which fits best:

❒ 1–12 months ❒ more than 12 months

- In which suburb/town is the community mental health service? _____

Based on your experiences with THIS community mental health service in the last six months, rate how you feel about each, indicating if you think it needs major improvement, some improvement, or no improvement.

These first few items are about improving access to the care you need:

1 The ease of getting the services and supports I need …

2 The ease of accessing help from the service in a crisis …

These next few items are about improving the treatment and care you receive at the service:

3 How well the doctor listens to me …

4 The ease of seeing a doctor when I need to …

5 The amount of time staff spend with me …

6 The level of respect staff show for me …

7 How well staff listen to me …

8 The sense of hope staff show for my future …

9 The opportunities for me to have input into my own care …

	Needs major improvement	Needs some improvement	Needs no improvement
10 The encouragement staff give me to join consumer focussed programs (for example: support groups, drop-in centres, phone lines, self-help, peer support, consumer advocacy groups) …	●	●	●
11 The opportunities for my family/carer to be involved in my treatment when I want …	●	●	●
12 How safe I feel when I am in contact with this mental health service …	●	●	●
13 How safe I feel in raising concerns with the service when I have a problem …	●	●	●
14 The service's willingness to address problems …	●	●	●

The next few questions are about improving the information provided by services:

15 The amount of information I get about my mental illness and treatment …	●	●	●
16 Information about my rights and responsibilities …	●	●	●
17 Information about mental health services and programs available …	●	●	●
18 Information about other support services (eg: housing, employment, family support, Centrelink etc) …	●	●	●
19 Information about how to maintain my mental health …	●	●	●
20 Information about who to contact in a crisis …	●	●	●

The next question is about improving privacy:

21 How well my personal information is kept private …	●	●	●

The next questions are about improving choice of treatment:

22 The amount of information I get about different types of treatments available …	●	●	●
23 The choices I have about the treatment I receive …	●	●	●

… continued overleaf

In this last section, please feel free to make any comments about the community mental health service you receive:

24 Overall, what do you think of the support you receive from this community mental health service?

25 What do you like least about the services you receive here?

26 What do you like most about the services you receive here?

27 Do you have any other suggestions for how the service could improve?

These last questions come from the NSW Health Survey and are about your overall view:

28 In the last three months have you attended a hospital emergency department (or casualty) for your own mental health care?

❒ Yes ❒ No ❒ Don't know

If yes, overall what do you think of the care you received at this emergency department?

❒ Excellent ❒ Very good ❒ Good ❒ Fair ❒ Poor ❒ Don't know

29 Overall, what do you think of the care you received at the community health centre?

❒ Excellent ❒ Very good ❒ Good ❒ Fair ❒ Poor ❒ Don't know

Thank you for your time and comments.

MH-CoPES questionnaire for people using inpatient services

Your opinion will help create better services and better outcomes: this is your opportunity to help mental health services improve in Sydney South West Area Health Service.

This questionnaire will gather your views about the inpatient mental health service you recently used. *Filling in this questionnaire is voluntary.*

Privacy guarantee:
If you choose to complete the questionnaire, NSW Health guarantees that your privacy will be maintained.

- Your completed questionnaire will go to an organisation independent of the health service – the hospital will not see your completed questionnaire.
- No names will be used on the questionnaires.
- Reports will not identify individuals.

How will the information I give be used to improve services?

- Every Area Mental Health Service will receive a summary report showing all the things people have said need improvement.
- Each service is then expected to work with consumers to make improvements based on the summary report.
- Summaries of the information will be publicly reported.

How do I fill it in?

- You will be asked to say what needs to be improved, from YOUR OWN EXPERIENCE.
- To answer most of the questions, just choose the coloured circle that is the best answer for you:
  - The red circle means *this needs major improvement*
  - The yellow circle means *this needs some improvement*
  - The green circle means *this needs no improvement*

For example, Q1 says:
The ease of getting the services and supports I needed …

If you feel this was something that needed some improvement, you would mark the yellow circle with a cross, like this:

To return the questionnaire:

- Please do not give it to back to the service
- Put it in the return envelope included and return by mail.

If you want help to fill in the questionnaire you could: (options to come later)

If you want your opinions to be included in a summary report to the specific service you used, please complete this section. If you only want your opinion to be included in the summary for the whole Area, please go to Q1.

- In which suburb/town was the hospital? _____
- How long did you spend in hospital on THIS occasion? Tick which fits best:

  ❒ less than 1 week ❒ 1 week–1 month ❒ longer than 1 month
  please specify how many _____
- How long have you been using mental health services? Tick which fits best:

  ❒ 1–12 months ❒ more than 12 months
- Did you fill this questionnaire out:

  ❒ while still in hospital ❒ after leaving hospital

Based on your experiences during your LAST hospital stay, rate how you feel about each item, indicating if you think it needs major improvement, some improvement, or no improvement.

The first few questions are about improving the treatment and care in hospital:

1 The ease of getting the services and supports I needed …

2 How well the doctor listened to me …

3 The ease of seeing a doctor when I needed to …

4 The amount of time staff spent with me …

5 The respect staff showed to me …

6 How well staff listened to me …

7 The sense of hope staff showed for my future …

8 Opportunities for me to have input into my own care …

9 The encouragement by staff for me to join consumer-focussed programs (for example: support groups, drop-in centres, phone lines, self-help, peer support, consumer advocacy groups) …

		Needs major improvement	Needs some improvement	Needs no improvement
10	The opportunities for my family/carer to be involved in my treatment when I wanted …			
11	How safe I felt in hospital …			
12	How safe I felt in raising concerns with the service if I had a problem …			
13	The service's willingness to address problems …			

The next few questions are about improving the information provided by services:

14	The amount of information I got from staff about my mental illness and treatment …			
15	Information about my rights and responsibilities …			
16	Information about mental health services and programs available …			
17	Information about other support services (eg: housing, employment, family support, Centrelink etc) …			
18	Information about how to maintain my mental health …			
19	Information about who to contact if I experience a crisis …			

The next question is about improving privacy:

20	How well my personal information was kept private …			

The next questions are about improving choice of treatment:

21	The information given to me about different types of treatments available …			
22	The choices I had about the treatment I received …			

The next questions are about improving leaving hospital and going to the community:

23	How much I was involved in planning for leaving the hospital …			

If you have not yet left hospital, please go to Q25 next.

24	How well the supports I needed when I left the hospital were arranged …			

… continued overleaf

In this last section, please feel free to make any comments about the hospital services you received.

25 Overall, what do you think of the care you received during this hospital stay?

26 What did you like least about your stay?

27 What did you like most about your stay?

28 Do you have other suggestions for how the hospital can be improved?

These last questions come from the NSW Health Survey and are about your overall view:

29 In the last three months have you attended a hospital emergency department (or casualty) for your own mental health care?

☐ Yes ☐ No ☐ Don't know

If yes, overall what do you think of the care you received at this emergency department?

☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ Don't know

30 Overall, what do you think of the care you received at this hospital?

☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ Don't know

Thank you for your time and comments.

SECTION 6

Recommendations

Based on the findings of the MH-CoPES project, Stage 1, the following recommendations are made for developing opportunities for consumer evaluation of mental health services in NSW.

1. Adopt the principles of consumer evaluation to guide all further development of the MH-CoPES Framework for Consumer Evaluation of Mental Health Services, and tools (see section 3 of this report for discussion of the principles, and section 4 for MH-CoPES Framework);
2. Trial the MH-CoPES Framework for Consumer Evaluation of Mental Health Services within AHS mental health services, to continue development of a robust statewide framework, and ensure consumer participation in evaluating mental health services is a routine part of quality improvement and service planning as the *National Standards for Mental Health Services* require;
3. Clarify the role and place of consumer evaluation of mental health services through the MH-CoPES Framework for Consumer Evaluation in service improvement, and continue to build a united vision and partnership approach between the Centre for Mental Health, AHS mental health services and consumers, plus other stakeholders, for consumer evaluation through MH-CoPES;
4. Pilot the Questionnaire developed at Stage 1 to establish its validity, reliability and associated properties, and develop the Questionnaire more fully in context (see section 5 of this report for questionnaires developed for piloting);
5. Develop and trial alternative methods of data collection and feedback tools, particularly verbal options, for consumers to give their feedback, which will provide comparable information in parallel to the questionnaire method developed in Stage 1;
6. Develop and trial differing modes of questionnaire administration;
7. Support the ongoing development of the MH-CoPES Framework for Consumer Evaluation through access to the expertise of InforMH to support establishment of process management and data analysis procedures;
8. Work with AHS mental health services and other key stakeholders across NSW to develop and trial reporting and feedback protocols for MH-CoPES data, collected through implementing the MH-CoPES Framework for Consumer Evaluation;
9. Work with AHS mental health services and other key stakeholders across NSW to develop and trial action and response protocols for MH-CoPES evaluation; and
10. Assess the training needs within mental health services relating to MH-CoPES consumer evaluation and develop training protocols to support implementation of the MH-CoPES Framework for Consumer Evaluation.

6.1 **Key issues and strategies for consideration**

This section details further specific recommendations from the TWG and is included in this report for consideration by NSW Health. NSW Health will take these issues into consideration during the next stage of MH-CoPES.

The TWG anticipates that successful implementation of consumer evaluation of mental health services via MH-CoPES will be the result of collaboration and partnership between all stakeholders involved in mental health services. It is the TWG's opinion that once trialled, NSW Health should adopt the MH-CoPES Framework for Consumer Evaluation of Mental Health Services to ensure consumer participation is a routine part of quality improvement and service planning as the National Standards require (see section 4 of this report for a detailed description of the MH-CoPES Framework for Consumer Evaluation of Mental Health Services).

The MH-CoPES TWG has identified a number of key strategies and issues for consideration by the Centre for Mental Health, NSW Department of Health, in partnership with mental health consumers and services, carers, NGOs and other key stakeholders, which should be investigated and considered during the next stages of the project.

6.1.1 State wide implementation

Stage 1 of the MH-CoPES project has highlighted the following issues as key to implementation of consumer evaluation of mental health services at a state wide level.

Integration with state wide information development system.
Integrate MH-CoPES with the state wide information development system, while recognising the distinction between consumer evaluation of services and outcomes assessment. It is the TWG's view that these activities are independent components of a full mental health information system, and service quality improvement focus.

Independent, consumer-directed management.
Support the establishment of an Independent Consumer-Directed Organisation to manage MH-CoPES data collection, return and analysis, and to take a lead role in developing reports for AHS, mental health services, NSW Health, and the public. This organisation should work closely with all relevant stakeholders.

State wide coordination.
Establish a state wide steering committee whose role will include support and coordination of MH-CoPES through establishing and maintaining a network to connect people involved within local MH-CoPES initiatives, and to develop templates and role descriptions to assist local implementation.

Service responsibility.
Build engagement in the full cycle of MH-CoPES evaluation of mental health services into performance agreements between NSW Health and Area Mental Health Directors. These agreements should include the following elements:

participate in dissemination of questionnaires and alternative methods for consumer feedback, and

demonstrate evidence of action plans and service improvement initiatives in response to MH-CoPES reports.

6.1.2 Area implementation

Two key issues have been identified as priorities for Area-wide implementation, with the following strategies recommended by the TWG for consideration:

Quality and participation.
Integrate MH-CoPES into routine quality improvement and participation initiatives at local AHS, mental health service level; and

Local management.
a. Establish local management and implementation steering groups at AHS, mental health service levels, to guide and champion consumer evaluation through MH-CoPES. These groups must include consumer membership; and
b. Establish dedicated MH-CoPES positions within local AHS, mental health services to ensure clear service commitment, responsibility and support of the process.

6.1.3 Developing evaluation options that are fully inclusive of special population groups and other stakeholders

The following strategies have been identified as priorities by the TWG for development of a fully inclusive model of service evaluation to be considered:

develop tools and processes for consumer evaluation of mental health services appropriate for other cultural and language groups;

develop tools and processes appropriate for consumers of child and adolescent mental health services, and older person's mental health services, to ensure consumer evaluation of mental health services across the lifespan;

develop a framework and appropriate tools for carer evaluation of mental health services; and

consider how feedback from those people who experience mental health problems in NSW but choose not to use, or are excluded from use of NSW mental health services, can be obtained, and used as part of quality improvement processes.

SECTION 7

Conclusions and the future direction for MH-CoPES

This report and recommendations are the final outcomes of Stage 1 of the MH-CoPES project. Further negotiation and development relating to the issues raised here is needed. What is intended is that this report and the recommendations made provide a guide for the next steps in achieving consistent state wide opportunities for consumers to participate in service quality improvement. Stage 2 of MH-CoPES will need to include analysis of the funding and resource implications and alternatives, and the viability of the recommendations produced in Stage 1.

Future stages of MH-CoPES need to follow on from the work conducted in Stage 1 to identify the funding and resource implications of the suggestions made about consumer evaluation in this report and to understand the options and alternatives and their implications for services and consumers.

The MH-CoPES Framework proposes a way forward for consumers to have a genuine opportunity to provide feedback about their experiences of services. The Framework also suggests how this feedback should fit within continuous quality improvement processes, to be one part of the efforts to create better mental health services in NSW. Further work on the Framework in Stage 2 will clearly define the options and components of each of the steps of the evaluation cycle.

A range of steps are suggested to continue the work that has started, reported here. The TWG, in consultation with the NSW Department of Health, has developed a proposal for Stage 2 of the MH-CoPES project. The second stage of MH-CoPES will aim to develop MH-CoPES consumer evaluation ready for use in mainstream practice in NSW Mental Health Services, by building on the developments in consumer evaluation of mental health services achieved in MH-CoPES Stage 1. Stage 2 will produce an agreed, fully articulated MH-CoPES Framework for Consumer Evaulation of Mental Health Services suitable for implementation across public mental health services for adults in NSW. Stage 2 will complete the development phase of the Framework and Questionnaires, ready for implementation across NSW.

The objectives of Stage 2 of the project will be to:

1. clarify the role and place of MH-CoPES in service improvement, and build a united vision and partnership approach between the Centre for Mental Health, AMHS and consumers, articulated in a clear policy position about consumer evaluation of mental health services;
2. clearly identify and document the properties and standards, and cost implications, of each phase of the MH-CoPES Framework for Consumer Evaluation of Mental Health Services (Data Collection; Data Analysis; Reporting and Feedback; and Action and Change), which will include:
    a. Exploring alternative forms of data collection to the Questionnaire (eg: by focus groups etc) and reporting on these alternatives;
    b. Piloting the Questionnaire developed at Stage 1 to test and refine the draft ready for use in services;
    c. Working with AMHS and other key stakeholders across NSW to develop Reporting and Feedback protocols for MH-CoPES data;
    d. Working with AMHS and other key stakeholders across NSW to identify and develop Action and Response protocols for MH-CoPES evaluation;
    e. Developing a clear budget which costs implementation of the Data Collection, Data Analysis, and Reporting and Feedback phases of the MH-CoPES Evaluation cycle.
3. assess the training needs in AHS mental health services relating to MH-CoPES consumer evaluation and develop training protocols to support the future implementation of the programme.

It has become clear 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. National and state policies already support this shift in culture and it is evident that many dedicated consumers, careres, and mental health workers also support this shift. Changing the culture of mental health services, however, will continue to be a challenge. Reviewing the literature and consulting with key stakeholders around NSW has demonstrated that consumer evaluation of mental health services is a complex task that will require creative, flexible, solutions with consumers and services fully engaged in partnership to address the problems services face, and build services that reflect the changing needs of their communities. The MH-CoPES project Stage 1 is one step towards achieving this.

"Consumers have a democratic right to exercise a voice about their health treatment and their health services, but also…hearing the voices of consumers is an effective way for [services]…to get good information about what needs to be done to improve the quality of their services"[127]

SECTION 8

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SECTION 9

Appendix A: list of tables

SECTION 10

Appendix B: list of figures

SECTION 11
Glossary

CAG:	Consumer Advisory Group. See also NSW CAG.
CMH:	Centre for Mental Health, NSW Department of Health
Consumer:	In this report, the term consumer is used to refer to a person who has experienced mental/emotional distress and who currently receives services from public mental health services in NSW. The term is not used in this report to include carers or family members of a person who has experienced mental emotional distress
InforMH:	The service that centrally manages collection and analyses of mental health service information for NSW Department of Health
MH-CoPES:	Mental Health Consumer Perceptions and Experiences of Services
MHOAT:	Mental Health Outcomes Assessment Training/Tools
MHOAT CCC:	Mental Health Outcomes Assessment Training/Tools Consumer Consultative Committee
MHSIP:	Mental Health Statistics Improvement Program
MMHRC:	MHSIP Mental Health Report Card
NGO:	Non Government Organisation
NSW CAG:	New South Wales Consumer Advisory Group – Mental Health Incorporated. NSW CAG is a non-government organisation that provides an ongoing mechanism for consumer and carer input into mental health policy, service development, and evaluation. NSW CAG was incorporated on July 29, 1994, under the Associations Incorporation Act (NSW) 1984.
TWG:	Technical Working Group

SECTION 12

Appendix D: list of conference presentations given by TWG members

MH-CoPES presented by Gillian Malins and Shirley Kirk at the 9th NSW Rural Mental Health Conference, March 16–18 2004, Armidale NSW.

MH-CoPES presented by Gillian Malins and Phil Escott at the NSW NGO Conference, 25–26 March 2004, Wollongong NSW.

MH-CoPES: Mental Health Consumers' Perceptions and Experiences of Services poster presented by Gillian Malins and Allison Kokany at 10th Annual Hunter Mental Health Conference, 14th May 2004, Newcastle NSW.

MH-CoPES: Better Services, Better Outcomes presented by Gillian Malins and Michelle Cleary at the 14th Annual Central Sydney Area Mental Health Winter Symposium, 22nd and 23rd July 2004, Sydney NSW.

Mental Health Consumer Perceptions and Experiences of Services, the MH-CoPES Project, presented by Gillian Malins as part of workshop entitled: Cultivating Change through Consumers' Perceptions, Experiences and Outcomes at 14th Annual TheMHS Conference, 1st–3rd September 2004. Gold Coast, QLD.

MH-CoPES: Consumer Directed Evaluation of Mental Health Services by Gillian Malins and Douglas Holmes at the Health Outcomes 2004: Perspectives on Population Health, 10th Annual National Conference, 15th–16th September 2004, Canberra ACT.

The Transforming Terrain of Mental Health Partnerships presented by Gillian Malins and Martyn Wilson at the Australian and New Zealand College of Mental Health Nurses International 30th Conference 20–24th September 2004, Canberra ACT.

Building consumers' voices into needs assessment in New South Wales, presented by Gillian Malins at the World Psychiatric Association section of Epidemiology and Public Health meeting, 7th July 2005, Brisbane QLD.

Mental Health Consumer Perceptions and Experiences of Services: challenging our methods of evaluation, presented by Gillian Malins at Health Outcomes 2005: Making a Difference, 11th Annual National Conference, 17th-18th August 2005, Canberra ACT.

Services moving to a consumer rhythm: Mental Health Consumer Perceptions and Experiences as part of services continuous improvement (MH-CoPES) presented by Susan Palmer and Gillian Malins at 15th Annual TheMHS Conference, 31st August–2nd September 2005, Adelaide SA.

SECTION 13

Appendix E: list of presentations to forums/meetings

NSW Health, Centre for Mental Health MH-OAT Consumer Consultation Meeting, 18th February 2004.

NSW Health, Centre for Mental Health, Mental Health Information Forum, 22nd April 2004.

NSW Health, Centre for Mental Health MH-OAT Consumer Consultation Meeting, 10th May 2004.

NSW Health, Area Mental Health Directors Meeting, 28th May 2004.

NSW Consumer Workers Forum, 18th June 2004.

Australian Health Ministers' Advisory Council, National Mental Health Working Group, Information Steering Committee, 56th Meeting, 4th October 2004.

NSW Department of Health, MHCIP Workshop, 23rd February 2005.

NSW Health – Managers of Consumer Participation Forum, 29th July 2005.

NSW Health, Centre for Mental Health MH-OAT Consumer Consultation Meeting, 7th September 2005.

SECTION 14

Appendix F: list of stakeholder consultations

Yass
Thursday 30th September 2004 from 10am to 3pm
Yass Hospital, Conference Room

Bega
Friday 1st October 2004 from 10am to 3pm
Bega Valley Hospital, Conference Room

Broken Hill
Monday 8th November 2004 from 11.30am to 4.30pm
The Centre for Community, Broken Hill

Morisset
Monday 22nd November 2004
Morisset Consumer Group Meeting

Port Macquarie
Monday 29th November 2004 from 10am to 3pm
Port Macquarie Health Campus

Tamworth
Tuesday 30th November 2004 from 10am to 3pm
Crittenden Cottage, Billabong Clubhouse

Griffith
Wednesday 8th December 2004 from 10am to 3pm
Griffith Base Hospital NTS

Central Sydney
Tuesday 22nd February 2005 from 10am to 3pm
Rozelle Hospital, Conference Centre

Newcastle
Friday 25th February 2005 from 10am to 3pm
James Fletcher Hospital, Conference Centre

Penrith
Wednesday 2nd March 2005 from 10am to 3pm
Education Department, Penrith District Office

Liverpool
Friday 18th March 2005 from 10am to 3pm
Thomas and Rachel Moore Education Centre at Liverpool Hospital.

NSW HEALTH

CONSUMER ADVISORY GROUP NSW CAG

MHCoPES

A statewide approach to measuring and responding to consumer perceptions and experiences of adult mental health services: a report on stage one of the development of the MH-CoPES framework and questionnaires September 2006