

# MH-CoPES Interim Report

Measuring and Responding to Consumer Perceptions  
and Experiences of Services



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Earlier reports relating to the MH-CoPES project referred to in this interim report can be obtained by contacting the MH-CoPES Project Officer:

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## 1 Introduction

The MH-CoPES project is an 18-month project being conducted by the NSW Consumer Advisory Group – Mental Health Inc. in partnership with the Centre for Mental Health, NSW Health. The project commenced in January 2004, and is due to make recommendations to NSW Health in mid-2005. The purpose of this interim report is to provide an update for key stakeholders on the progress of MH-CoPES, outlining the directions the project team is taking to develop recommendations relating to a state wide approach to consumer evaluation of mental health services.

In this report, the background to the project will be described, as well as the process the project team has adopted in conducting the project. This process is reflected in the principles underpinning MH-CoPES, which are described in detail in section 3. These principles will guide the recommendations made by the MH-CoPES team, but have also guided the research process engaged in since January 2004.

## 2 Background

### ***2.1 MH-CoPES aim and context***

MH-CoPES aims to develop a state wide approach for mental health services in NSW to hear and respond to consumers' views about services, as part of their continuing improvement processes. Achieving this aim includes making recommendations about what tools and processes services could use to accomplish genuine consumer input into service planning, provision, and improvement.

The vision for the MH-CoPES project is:

- 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.

Essentially, the MH-CoPES tools and process will complement existing quality processes already in place in NSW, contributing a further mechanism by which service quality can be monitored and managed. The MH-CoPES approach will explicitly contribute to the existing quality processes by providing a means for consumers' voices to be heard, and impact on the way services operate. Other projects are required to develop approaches to hearing and understanding other key stakeholders perspectives, importantly carers' and staff. The MH-CoPES

tools and process will stand alongside those developed by these future projects. Importantly, as this report outlines, MH-CoPES has focused specifically on understanding and developing tools for consumer evaluation in adult mental health services. Future efforts will need to also focus on issues of consumer evaluation specific to children, adolescents, as well as older consumers, and developing tools and processes that are suitable for people from culturally and linguistically diverse backgrounds, and indigenous consumers.

While for consumers, outcomes and experiences of services are often closely related,<sup>1</sup> the MH-CoPES tools and process will specifically focus on consumers' perceptions of the services they use. We argue that consumer evaluation should be considered a service outcome rather than an individual outcome. That is, consumers' evaluations of services should be seen as more reflective of the state and performance of the service, than an indicator of the consumers' mental health or recovery. Others in the field support this view of consumer evaluation of services.<sup>2</sup>

The MH-CoPES project has its background in several areas that have developed in the mental health field over past decades, most particularly:

1. the growing recovery orientation;<sup>3-7</sup> and
2. the increased focus on participation and partnership in health care at international and national levels,<sup>6, 8-17</sup> which has its roots in the Alma Ata Declaration of 1978.<sup>18</sup>

Recognition of the importance of using consumer feedback in service improvement is not new: integral to the model of consumer participation developed by Wadsworth and Epstein<sup>19</sup> and further elaborated by Epstein and Shaw<sup>20</sup> is that consumer participation should be intrinsically linked to quality assurance activity.

## ***2.2 Our approach to conducting the MH-CoPES project***

The approach adopted to conduct the MH-CoPES project is collaborative and participatory. Primarily, the approach is consumer-directed. This is reflected in the overarching partnership between NSW CAG and NSW Health, Centre for Mental Health, with the consumer and carer organisation, NSW CAG, funded to lead the project. The structure of the Technical Working Group (TWG) is also reflective of the collaborative, consumer-directed approach that has been adopted: the TWG has a strong consumer representation, but reflects a mix of the stakeholders involved in mental health services.

The TWG was established in late 2003, and with guidance from NSW CAG spent their first meetings establishing the group and determining the job description for the Project Officer position. The Project Officer commenced work in January 2004, and the team has met on a regular basis since. The principles underpinning consumer evaluation, outlined in the following section, are also reflective of the approach we have adopted in conducting the project, and have guided decision making by the TWG.

### 3 The Principles underpinning MH-CoPES

Nine interconnected principles underpin the evaluation of mental health services (MHS) by consumers, and thus MH-CoPES. These principles are:

**Recovery Orientation.** The concept and process of consumer evaluation comes from a recovery focus. A recovery orientation to service provision means that at a systems level mental health services are to be guided by consumers' views of what works and what does not. This means that 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, funders, 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; and

**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.

Each principle is 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).<sup>4</sup> We see 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:

- a belief that consumers hold the key to recovery, not professionals;
- that professionals 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;
- recovery is not a linear process;
- recovery is also about consequences of the illness, not only symptoms; and
- that the concept of recovery is not synonymous with a finite, 'no symptoms' type of state, which means recovery can occur even if symptoms reoccur.<sup>4, 5</sup>

Davidson et al<sup>21</sup> 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 professionals 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. We 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, meaningful mental health services. Historically, it has been demonstrated that consumer definitions of quality and the health services definitions of quality do not match<sup>22</sup>. 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<sup>23</sup> discussion of citizenship and rights. Citizenship is enacted through participation in MH-CoPES. Consumer participation has been increasingly recognised as fundamental to good mental health services internationally 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), but essentially helps people gain control over their own lives. Nelson, Lord and Ochocka<sup>24</sup> 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 team’s perspective, it is important that the concept of power is not viewed as “all or nothing”, finite. Genuine consumer participation as an underpinning principle of evaluation of mental health services is essential because it builds a forum where consumers have actual 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 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. We see this as an opportunity for both individuals, and local communities to become empowered.

### **Accountability**

Being accountable involves services taking responsibility and being answerable: 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 method and 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, and 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 – continual working towards making a service better. 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. So, continuous improvement is an activity that never stops: expectations of services will also 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, we believe that improvement is 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 holds 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 we maintain that individual privacy is essential, it is important to consider the implications of accountability and transparency in conjunction with this principle. While we acknowledge that privacy can be a serious concern in terms of reporting for smaller services, this principle should not be used by services to

hamper 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 it's 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 the overall evaluation process, but also to individual components of the process, including reporting, action phases, and data collection. 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 it sets out to, which is guiding change within mental health services – locally and at a statewide 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.

## **4 The Key Activities of the MH-CoPES Project**

To achieve our overall aim and objectives, nine key activities or goals were identified in the original project brief for the project's Technical Working Group (TWG) to engage in. These have guided the progress of the project to date, and include:

1. Define clear criteria to evaluate existing tools, and/or develop a new tool;
2. Conduct a literature review on measures, methods, tools etc.;
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;
7. Modify tools based on stakeholder feedback, draft report;
8. Hold a state-wide targeted workshop to comment on the proposed tool/s;

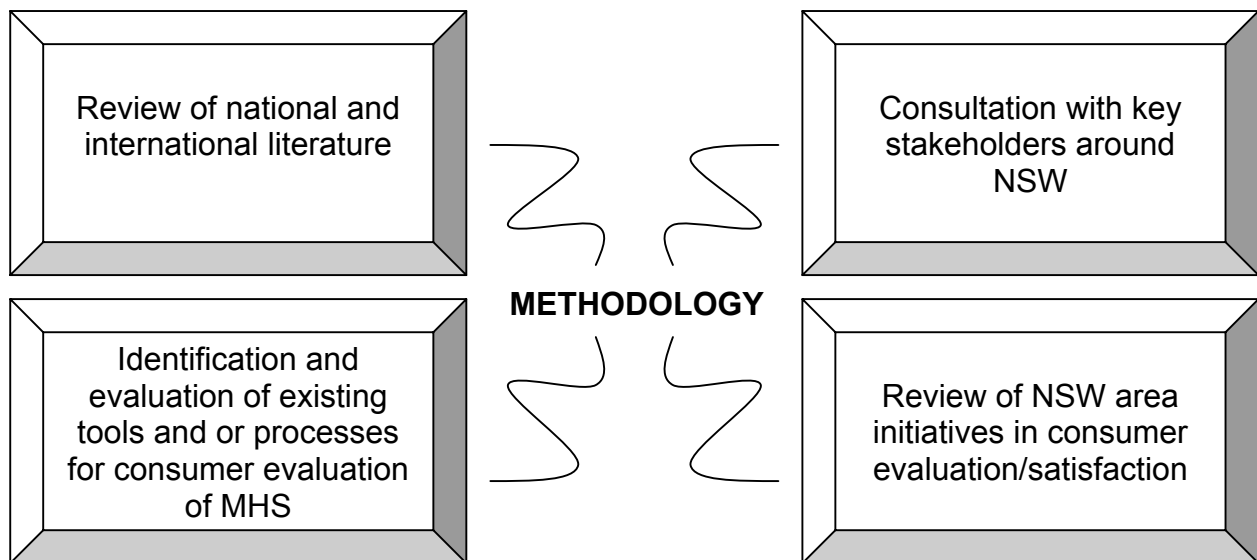
- and
9. Produce a final report.
- In addition to the original nine key tasks, the TWG, once assembled, added a further two tasks that span the life of the project, which are:
10. Consult, inform and update key stakeholders; and
  11. Project evaluation.

While some of these key activities occur sequentially, many necessarily occur in parallel. Since January 2004, the team's major focus has been on completing goals 1 to 4, and this report itself represents Goal 5.

The remainder of this report will describe the work conducted to date towards achieving these project goals, and additionally, will act as a focus for discussions determining the way forward with the remaining key tasks for the project.

## 5 Development of the MH-CoPES tools and processes

Four main methods are being used to develop the draft MH-CoPES tools and processes for discussion at the Statewide workshop, due to be held in April 2005 (see Goal 8). These are shown in Figure 1. These methods are reflected in the various key activities for MH-CoPES outlined in section 4 of this document, and more detail is provided about the key activities in the remainder of the report.



**Figure 1. Methodology used to develop the draft MH-CoPES tools and processes**

## **6 Defining criteria to evaluate existing methods and measures, or to direct development of new tools and processes**

For a full discussion of the background literature relating to the development of the MH-CoPES criteria for evaluating existing tools and processes, please refer to Interim Report # 1.

In defining criteria to apply to evaluating or developing tools and processes for MH-CoPES, it was established that consistency with the project's purpose was essential. This meant that the criteria needed to assist the project team identify a "performance management system" rather than simply a "performance measurement system".

In a report to the Joint Legislative Audit and Review Committee, Washington State, in 2000, the Center for Clinical Informatics<sup>25</sup> outlined nine key principles to developing and operating good performance management systems (in contrast to only monitoring performance, or quality). These principles are: Measure to manage; Management requires regular feedback; Keep it simple and make it matter; Keep it brief, measure often; Create benchmarks; compare results; Provide the right information at the right time to the right person to make a difference; Create flexibility so that the system can evolve with the experience of users; Maintain central control of data and reporting; Establish and protect a core data set. Performance management, or continuous quality improvement, relates to data being used in service improvement efforts.

As well, a range of well-established criteria exist, relating to measurement systems. These converge around the following points. Tools should:

1. Ask about domains that are identified as important by the people for whom the tool is developed.

The tool and process will specifically focus on the areas of service delivery, outlined in the original project proposal, relating to:

- Availability of services;
- Access to services;
- Getting information;
- Treatment and assistance;
- Staff; and
- Participation.

2. Be comprehensive.

The tools and processes need to provide an opportunity for consumers to comment and impact on a wide range of issues relating to service provision.

3. Be practical to use, and flexible enough to be used by a range of people in a range of settings and organisations.

In terms of being practical, the tool and process needs to be a reasonable length to provide useful detail to consumers, services and the state, but at the same time be able to be completed by consumers in a suitable time period.

Judgements of whether a tool is practical need to be made by all stakeholders involved: which includes consumers as well as service staff and management.

The tool and process will need to be adaptable to the needs of individuals across the lifespan, and across acute care, long-term settings, in-patient and community contexts.

4. Be culturally sensitive and appropriate.

People who use mental health services in NSW come from a diverse range of cultures. The tool and process needs to be appropriate for any consumer to complete.

5. Be valid, reliable and sensitive to change.

One of the key measures of validity for the tools recommended by MH-CoPES will be face validity, provided by consumers. Face validity, if determined by consumers, relates closely to the criteria of being applicable and acceptable.

Other measures of validity that are applicable in this case include content validity, particularly in terms of whether consumers were involved in item generation and development of a tool. Convergent and divergent validity will be of interest also for existing measures.

## **7 Reviewing the national and international literature**

For the full literature review conducted to date, please access MH-CoPES Interim Report # 2. Report # 1 also provides a review of further relevant background literature.

Reviewing the literature has led us to consider some of the limitations that the traditional approach of using consumer satisfaction surveys faces in achieving genuine consumer input. A number of limitations with satisfaction surveys are highlighted in the literature. These limitations include:

- The utility and sensitivity of satisfaction surveys has been regularly questioned due to consistently high levels of satisfaction found when these surveys are used.<sup>26, 27</sup>
- 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.<sup>28</sup> Lovell's findings call into question the accuracy of these surveys.
- Measures often have not been developed by consumers, based on issues relevant to consumers.<sup>28-31</sup> Hansburg et al<sup>30</sup> found when administering a consumer-developed survey versus a professionally developed survey, that satisfaction levels were lower when the consumer-developed survey was used.
- Satisfaction with services has been found to be lower when consumers administer satisfaction surveys compared to when staff administer the

surveys.<sup>26, 30, 32, 33</sup> 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 et al<sup>32</sup>, 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.

Two further key areas of literature reviewed as part of MH-CoPES are:

- Literature describing consumers' views and experiences with services. This included qualitative literature, and reviewing literature from the recovery and well-being areas. Some of the key points that arose from reviewing this literature included:

1. A focus much broader and encompassing than 'symptoms' and 'hospitalisation' is needed, for consumers' views and experiences of services to be heard.
2. Similarly, and closely related to the point made above, consumers' perceptions and experiences of services are difficult to separate completely from their perceptions and experiences of recovery. This suggests the need for holistic frameworks, rather than compartmentalising approaches. What this implies is that consumers need an opportunity to report on a broad range of issues that relate to their perceptions and experiences of mental health services, which will include "satisfaction" type issues, or evaluation of service provision features, as well as "outcome", defined in a sense more compatible with a recovery orientation, than symptom and hospitalisation focus.

- Literature describing approaches developed and/or in use internationally and nationally to produce instruments and processes for consumers to provide feedback and evaluation of the services they use. These are the focus of the following section, which relates to the third major project task.

## **8 Existing tools and processes**

In total, 29 tools and processes were identified during this stage of the project. Twenty of those identified came from the literature review conducted, and represent international and national efforts to produce instruments and processes for mental health services to hear and respond to consumers' views. Nine tools and processes were identified by conducting a survey of mental health services across NSW (both government and non-government agencies).

In identifying tools and processes for consideration, we were explicitly seeking 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 have been identified, and some of the

tools identified are available in formats for more than one of these age groups. One tool (the CLSS) 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 evaluating the tools and processes identified. In addition, the World Health Organisation Quality of Life brief measure (WHOQOL-BREF) was also included.

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

1. Satisfaction scales: the SERVQUAL,<sup>34</sup> Client Satisfaction Scales (CSQ; CSQ-8);<sup>35</sup> the Service Satisfaction Scale (SSS),<sup>36</sup> the Verona Service Satisfaction Scale (VSSS)<sup>37</sup>; the General Satisfaction Questionnaire (GSQ); the Patient Satisfaction Questionnaire (PSQ);<sup>38,39</sup> and the Patient Judgement System (PJS).<sup>40</sup>

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/services. These tools were excluded from consideration by the MH-CoPES team because of the range of issues our literature review highlighted relating to satisfaction scales and the satisfaction construct (see Interim Report # 2 for a full discussion of these issues).

2. Outcomes measures: the Behaviour and Symptom Identification Scale (BASIS-32);<sup>41</sup> Mental Health Inventory (MHI); SF-36;<sup>42</sup> 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.<sup>1, 43</sup>

The tools and processes identified through the literature review are listed in Table 1., and from our survey, in Table 2.

Table 1. Tools and processes identified through literature review for consideration by MH-CoPES project team	
Tool and/or process	Country of origin
Accountability and performance indicators for mental health services and supports <sup>44</sup>	Canada
Carers' and Users' Expectations of Services – User version. (CUES-U) <sup>45</sup>	UK
Community Living Skills Scale (CLSS) <sup>46</sup>	USA
Consumer Assessment of Behavioral Health Services instrument (CABHS) <sup>47</sup> *	USA
Consumer Evaluation of Mental Health Services (CEO-MHS) - Evaluation Framework & CEO-MHS- 26 <sup>48</sup> *	Australia
Consumer Expectations, Perceptions and Satisfaction Scale (CEPAS) <sup>49</sup> *	Australia
Consumer satisfaction of parents and their children <sup>50</sup>	USA
Inpatient Evaluation of Services Questionnaire (IESQ) <sup>51</sup> *	Australia
MHSIP Consumer Survey <sup>52</sup> *	USA
The Multidimensional Adolescent Satisfaction Scale (MASS) <sup>53</sup>	USA
Patient Perception of Hospital Experience with Nursing (PPHEN) <sup>54</sup> *	USA
Recovery Oriented System Assessment (ROSA) <sup>55</sup>	USA
Recovery Self-Assessment (RSA) <sup>56</sup> *	USA
Rome Opinion Questionnaire for Psychiatric Wards (ROQ-PW) <sup>57</sup> *	Italy
Satisfaction with Nursing Home Instrument (SNHI) <sup>58</sup> *	USA, Korea & Taiwan
THE U & I Model: A model for increasing evaluation of acute psychiatric hospital practice <sup>19</sup> *	Australia
User Focused Monitoring (UFM) <sup>59</sup> *	UK
The Victorian Consumer Survey <sup>60</sup> *	Australia
WHOQOL-BREF	Multi-national
The Youth Client Satisfaction Questionnaire (YCSQ) <sup>61</sup>	USA

Note: \* indicates tools used as item pool for consultation and development.

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

## 9 Evaluation of the tools and processes identified

An evaluation of the tools and processes identified was conducted by a small working party from the MH-CoPES TWG, in conjunction with the MH-CoPES project officer. Members of this working group initially conducted independent evaluations of the tools and processes according to the evaluation criteria the MH-CoPES team had defined, using the available literature relating to each tool.

After team members conducted individual assessments, this small working group held a single-day workshop, where the tools and processes, and team members' evaluations of them were discussed. The outcome of this workshop was a joint evaluation, with a set of recommendations for the TWG to consider.

The recommendations made to the TWG included:

- That the MH-CoPES TWG use a number of tools (identified by \* in Table 1) to form an item-pool, and generate an MH-CoPES tool from this item pool;
- Consideration of tools appropriate for collecting views of consumers of child/adolescent services to have further evaluation, perhaps seeking assistance from people in that field (ie. external to the TWG). It was also recommended that consultation with stakeholders relevant to child/adolescent services be conducted separately to other MH-CoPES consultation.
- That the MH-CoPES tool consist of a set of core-items, which fall into a minimum of 3 sections: the first section would include items relevant across

all service settings; the second section would include items specifically relevant to inpatient/hospital settings; and the third section would include items specifically relevant to community settings. Consumers should have clear instructions, which guide them to respond to those items/sections that apply to them.

- That qualitative/open-ended responses be used in written questionnaires, if this approach is adopted as a format for MH-CoPES data collection.
- Items adopted for MH-CoPES should provide an adequate level of specificity that they prove useful in guiding service change.

At the TWG meeting held in September 2004, these recommendations were considered, and used to guide decisions regarding the direction of the MH-CoPES team in achieving the remaining project tasks. A number of decisions were made at the project meeting:

- Our approach to consultation with key stakeholders was developed, informed by the recommendation to generate an item-pool from a number of existing tools. It was determined that stakeholders in consultation would be invited to assist the TWG to identify the most useful items for inclusion in MH-CoPES tools using this item pool.
- The team agreed that given the time frame of the project, consultation would commence primarily with stakeholders of adult mental health services. A number of issues relating to consulting with child and adolescent stakeholders were identified, and it was determined that these consultations needed to be conducted separately. Ongoing discussions within the TWG commenced relating to whether developing tools and processes for the entire set of age groups was feasible for the established group, in the current project time frame. These discussions led to negotiation with NSW Health, and a decision that the focus of the current MH-CoPES project will be to develop a generic set of tool/s and processes for consumer evaluation of mental health services primarily suitable for adult services, and that further projects will be necessary to conduct consultation and modification of these generic tools, for appropriate use with consumers across the life-span and to ensure the tools and processes are developed into culturally appropriate approaches to evaluation.

## **10 Consultation with key stakeholders in NSW**

Our approach to consultation with key stakeholders is guided by the background work described in this report, and our approach, which was previously described as being consumer-directed, participatory and collaborative. Our approach is consistent with what Hunt calls consumer health research,<sup>62</sup> which she describes as:

*“research conducted by and with consumers as opposed to research conducted on behalf of consumers”* (p. 48).

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. Appendix A shows these locations on a map of NSW Area Health Services at the time consultations were held. A range of stakeholders attended each forum, with consumers, carers, staff, non-government organisations, and allied health professionals all represented. Between five and thirty people attended any single forum.

### **10.1 A summary of issues raised in MH-CoPES consultation**

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, our consultations indicate 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.

#### **10.1.1 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.

Consumers in consultation identified a range of possible barriers to consumer involvement in evaluating the mental health services they use. These barriers included:

- Fear of retribution. 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 mental health services is also raised in the literature, by authors such as Lammers and Happell<sup>63</sup> and Tobin, Chen and Leathley.<sup>64</sup> 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.
- 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 like 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. Participants particularly highlighted differences between rural/remote and metropolitan services, and how consumers interact with them. 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 to make MH-CoPES successful.

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

- Devaluing of non-professionals viewpoints – not taking consumers’ perspectives seriously. Recent studies provide clear evidence that mental health workers “may still be unwilling to trust and respect the patient view”<sup>65</sup> or that consumer input can bring valuable contribution to service planning, delivery and change,<sup>63</sup> and this issue was also raised by stakeholders in consultations.

Perkins and Repper<sup>66</sup> 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 – and 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.”<sup>20, 67-68</sup>

- 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, based on a concept “mental illness” not “mental health”, despite their name.

Stakeholders argued in consultation 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 Technical Working Group, 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 underpin services. MH-CoPES should also support holistic views of consumers.

- Views of what quality is and where it fits in 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<sup>69</sup> provides support for this view, noting that “The Taskforce on Quality in Australian Health Care (Australian Health Ministers’ Advisory Council, 1996) 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, and 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 this information would bring.
- Lack of resources and a perception that “this is too expensive”. Participants identified that funding allocations and resourcing will need to be available to:
  - a) support consumer evaluation activities, and
  - b) create the changes evaluation suggests are necessary.Without adequate funding, consumer evaluation of services cannot genuinely occur, and achieve results. It was also recognised, however, 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<sup>70</sup> report on the effective use of changing information and communication approaches to address consumers’ negative views of waiting times in an emergency

setting. Consumers in our consultations stressed that often what is lacking in the services they have received is information about what will happen and why – and a chance to have their say about this. Many people in consultation said although they may not always like everything that occurs, knowing what to expect and being able to understand why it will happen makes a big difference to their experience.

- Differing concepts within and between services of what level of information is required to be useful. It was suggested that this will 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 see 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, also, is how anonymity and confidentiality are achieved and maintained. If follow up of participants cannot be carried out to achieve anonymity, research suggests there will be significant cost to response rates. Phone follow-up is the primary form of low-cost follow-up evident within the literature, with demonstrated impact on response rates. However, if it is not known who has returned a questionnaire and who has not, two options are available. All consumers could be phoned, and reminded, with an apology if they have already completed and returned a questionnaire, which is a time consuming and costly option; or no phone 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 itself, and changes to service provision difficult.
- Problems of short staffing (often perceived in terms of lack of time or resourcing also) 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.

### **10.1.2 Overcoming the barriers and identifying factors that support consumer evaluation in mental health services**

Participants in consultation made a number of suggestions for ways MH-CoPES may overcome some of the barriers identified, and assist in making evaluation trustworthy and useful. These suggestions include:

- High consumer involvement in implementation.
- Independent organisation being responsible for collecting and analysing data.
- Independent, consumer organisation to maintain ownership of data collection and feedback. 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.
- Receiving feedback about the results (that is, open reporting and wide dissemination of results) will also affect consumers' views of 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 etc), 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.
- That allied health and service partners be utilised to assist in informing consumers about MH-CoPES, and to act as access or pick up points for questionnaires. It was further suggested that some of these organisations could provide support to consumers in completing written questionnaires if consumers require assistance. While it appears that this is seen as a suitable and possibly preferable solution to many consumers and some service providers, concern at an area/state level has been expressed regarding the limiting effect this would have on statistical power and knowledge that those participating are indeed current consumers of public mental health services.
- 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.
- Use service partners like GPs and NGOs as collection points for consumers to drop-off/return completed questionnaires. This was suggested as an addition to supplying reply-paid postage envelopes as participants in consultation identified that getting questionnaires returned would prove a difficulty for MH-CoPES if this was left to consumers to carry through with. It was suggested that while providing postage-paid return envelopes would prove helpful, doubt was expressed regarding the return rate this would achieve.

- 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 consumers, and options for taking part in evaluating services should include flexibility to nominate a carer to assist or advocate for them at times.
- One choice in providing feedback on perceptions and experiences of services should involve talking with another/other consumer/s. Those consumers who participated in consultation suggested that typically consumers feel safe with, and trust, other consumers, and feel a sense that they will be 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 will possibly result in information about the experience of using services being gathered that would not otherwise be accessed.
- Create a flexible process, which can be adapted to different service needs, while also providing consistency across the state. 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.
- Strong education and information campaigns developed and implemented 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.
- Involvement of 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 identify areas the need work.

### ***10.2 Consultation in early 2005***

Further consultation forums are planned during early 2005, in a further five areas around NSW. These consultation forums will build on the feedback the project team has received in earlier forums. We are currently in the stages of developing the first tool, a questionnaire, for consumer evaluation of mental health services. The input and feedback of consumers and other key stakeholders in consultation forums during 2004, along with our review of existing tools, was used to construct an initial draft of the MH-CoPES tool/s. Consultations during early 2005 will refine and test this questionnaire with key stakeholders, and will also focus strongly on further development of the MH-CoPES process.

## **11 Conclusions and the future direction for MH-CoPES**

As we prepare this report, we are approaching Goal 8 of the MH-CoPES project, with a statewide workshop planned for 6<sup>th</sup> April 2005. This workshop will provide an opportunity for key stakeholders to be updated on the progress of MH-CoPES, and to comment on the tools and process as we move towards producing the final report for Stage 1 of the MH-CoPES project.

Reviewing the literature and consulting with key stakeholders around NSW has demonstrated to us 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.

It has become clear to us that implementing genuine consumer evaluation processes in mental health services in NSW will essentially be a shift in the current culture of services, toward fuller consumer and service partnership, and fuller consumer participation at all levels of services. Our national and state policy already support this shift in culture, and the MH-CoPES project is supported by a range of other initiatives around the state, working towards these broader goals. What this highlights for the future, however, is that consumer evaluation of services will need to be understood within broader change management frameworks to become a reality.

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## 13 Appendix A



**Figure 2. Map of 17 NSW Health, Area Health Services, 2004, downloaded from the NSW Health website, with locations of MH-CoPES consultations conducted in 2004 indicated.**

▲ Indicates approximate location on map of 7 MH-CoPES consultations held in 2004.