A FRAMEWORK FOR CONSUMERS EVALUATING MENTAL HEALTH SERVICES

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EXECUTIVE SUMMARY

Background

Nationally and internationally mental health policies and plans mandate consumer participation in a numbers of ways in mental health services. The National Standards for Mental Health Services (Commonwealth of Australia, 1997) includes 11 standards, the third of which is “Consumer Participation”. In terms of service evaluation Meadows et al., (1997) have stressed the need for mental health services to establish data on the needs of consumers, from a consumer perspective. Consumers are almost exclusively being asked to indicate their satisfaction with services by completing customer satisfaction surveys. Yet these surveys are not appropriate in mental health because, as Gill, Pratt and Liberera (1998) have demonstrated, there are differing results depending on whether staff or consumers administer the survey. There is also the deeper issue about who decides what goes in such surveys: staff or consumers.

To redress these identified shortfalls in the evaluation of mental health services this project was grounded in a values based approach based on the principles of equity and justice. This foundation ensured active rather than passive participation of consumers in the research project and privileged their expert knowledge gained from the lived experience of mental illness. Such an approach empowers mental health consumers by giving them a say in what questions about services are asked, and which aspects of services are evaluated and training them to collect the relevant data. Involving consumers in this way will hopefully lead to more effective health services, through focusing more directly on consumer needs, asking questions about services that mental health professionals do not think to ask and enabling consumers themselves to collect the data on health service outcome. Such research has not been undertaken before.

Aims and Objectives

The research project aimed to improve mental health services by empowering their consumers and demonstrating the as yet untapped resource of consumers as mental health researchers.

The objectives were: to develop a consumer driven and directed framework and quantitative instrument to evaluate mental health services; to utilise genuine collaboration between experienced researchers and mental health consumers to improve the validity of the data generated; to develop a practice manual for the training of mental health consumers in research; to develop locally a team of consumers trained in research skills; to develop locally a team of staff more aware of consumers views and capable of working with consumer researchers, and to provide internationally competitive publications documenting the various stages an components of the project.

Research Design and Methodology

The research design and methodology differed from evaluation that focuses on standard customer satisfaction surveys of mental health services in three major ways. First, the research began with a comprehensive qualitative data collection phase that allowed for the development of the quantitative tool, the CEO-MHS 26. Second, to increase the robustness of the qualitative data collection, focus groups were used in the formative phases of the research. Third, and most importantly, mental health consumers were used exclusively at all times for data collection and they drove the development of the CEO-MHS Evaluation Framework. The Consumer Researchers and some members of the project team used the information obtained throughout the research project to develop the CEO-MHS Evaluation Framework. In keeping with good evaluative practice, the mental health service, other consumers and the local community were kept informed about the projects outcomes.

Data collection and methods

The first phase of the project involved recruitment and training of 14 casual Consumer Researchers (CRs) to enable them to actively participate and drive the project. The CRs first task was to conduct focus groups with 20 consumer participants to help identify what criteria the consumers would use to evaluate mental health services. This step was undertaken in order to develop the interview questions. Purposive participant selection using the Maximum Variation Sampling technique was used to select the 33 interview participants from a variety of settings to ensure obtaining the greatest differences in the phenomenon being studied. This method was consistent with our goal of understanding in contrast to generalisation.

At the beginning of the project a much larger sample and more thorough psychometric testing was planned, however as the project progressed this was not feasible. The prime consideration in the development of the CEO-MHS 26, the quantitative instrument, was that it was brief and easy to use. It was developed in a number of stages to address issues of reliability and validity. The first step involved developing 4 questions for each of the 11 identified interview themes. This larger 44-item version of the scale was then trialled with 209 consumers, 100 from mental health services and 109 from non-government services.

The development of the evaluation framework has been ongoing since the commencement of the project. It has involved literature reviews, conducting focus groups and interviews with consumers, analysis of the data, development of the quantitative instrument the CEO-MHS 26, meetings to reflect on the process, and the documentation of the values, principles and steps of the CEO-MHS Evaluation Framework.

Analysis

Qualitative data analysis was most appropriate given the project's aim of understanding consumer's perspectives on mental health services. Hence the Interpretative Phenomenological Analysis method (IPA), which focuses on meaning and the interpretive nature of analysis, was chosen to analyse the focus group and interview data. Strict criteria were used to verify the data analysis. Eight themes were identified from the focus group data and these were used to develop the interview questions. Eleven interview themes were identified and these were used to develop the quantitative instrument, the CEO-MHS 26.

The statistical analyses of the larger 44-item quantitative instrument enabled it to be reduced to a more manageable and still meaningful 26-item questionnaire. These analyses provided some information on the psychometric properties of the instrument. While the CEO-MHS 26 is still in a preliminary stage of development, its factor structure has been established and a satisfactory internal consistency demonstrated. There is initial indication that the structure of the scale provides some support for its' content and construct validity. However the amount of variance accounted for by the two factors, while reasonable in the first instance, indicates the scale needs further developmental work.

Guba & Lincoln's (1994) Responsive Constructivist Evaluation partly influenced the development of the CEO-MHS Evaluation Framework that outlines 7 values, 10 principles and 12 steps necessary for effective consumer orientated mental health service evaluation. The CEO-MHS Evaluation Framework was being developed into a manual for publication at the time of writing.

Discussion

The overall aim of the project was to utilise the as yet untapped resource of consumers as mental health researchers, to develop a consumer driven and directed method of evaluating mental health services to lead to their improvement. We argued that to date consumers have not been considered credible and therefore they have been a largely untapped resource within the mental health system. The difference between this project and other projects, and what makes it unique, is that the consumers were not only employed and trained as researchers and collaborators, they actively drove the development of the Evaluation Framework, one of the major outputs of the project. Such an approach requires privileging the knowledge that comes from the lived experience of mental illness and hence valuing this 'expert' knowledge in a similar vain to 'expert' professional and academic knowledge. The values and beliefs underlying the project and outlined in the introduction, enabled the genuine participation and partnership that was required amongst project team members that we believe has taken consumer involvement in research to the next step of involvement in mental health system evaluation. That is, the project has provided a genuine consumer voice about the evaluation of mental health services.

It is important to reiterate here that the same negative stories of consumers experience with mental health services that have been found in a number of other qualitative studies were found in the focus groups and the interviews. This finding again leads to the conclusion that while a lot of effort has been put into consumer participation it appears their views and experiences are still not being adequately fed back into cycles of quality improvement in services as was found in Service Quality Australia (1999). Therefore it is reasonable to conclude that this problem has not been resolved because consumer views are still not being adequately integrated into service change processes. This supports our view that as well as adequate and appropriate survey instruments to elicit consumer’s views, such as the CEO-MHS 26, an explicit protocol is also needed that identifies how these findings will be implemented to effect service change. The CEO-MHS Evaluation Framework provides both.

RECOMMENDATIONS

The recommendations have been divided into two sets, general and procedural.

General recommendations

1. Through implementation of the model and framework, services will become more responsive to the consumers of their service. Consumers will guide the improvement. Ensuring input at this fundamental level will challenge existing power relationships.

2. Not only is there tension between consumers and professionals, there can be tensions between consumers and this seems to be according to their level of involvement in mental health issues and mental health research. Conflict resolution procedures need to be available within services.

3. There are a number of questions that have arisen as a result of this project and these warrant detailed discussion amongst key stakeholders. These questions follow:

   - Is there something about the balance of the driving forces for evaluation?
   - Does consumer driven then lend its self to some of the criticisms of professional driven?
   - Does it constitute partnership/collaboration if one group is not putting forward their views?
   - Is professional/researcher knowledge obsolete?
   - If not, then how is this knowledge to be accessed and utilised by consumers?
   - Do consumer researchers need to be familiar with the issues already identified by other consumers or do you start from scratch with local knowledge and what are the advantages and disadvantages either approach?

4. Future projects should consider building the capacity for consumers to be employed on a regular basis. This will allow for the greater cohesion of the group and the development of roles and responsibilities. It also allows for the project to be responsive to unforseen changes that arise from time to time in the project. Casual employment has downfalls. If consumer researchers are offered 40 hours work in 12 months they are likely to have other employment. This can lead to competing demands, make project organization difficult and hinder the formation of effective teams.

5. Genuine collaboration needs to be continually worked at, it does not just happen. This should be and agenda item on all meetings. Procedures need to be put in place to address inadvertent groups forming within the project team. Training through workshops with role-play and role reversal, with annual booster sessions would be helpful.

6. In relation to the training of consumers to be researchers it is recommended the training be spread over a longer period of time than occurred in this project. When using focus groups to determine training needs facilitators need to be mindful of factors that may inhibit open discussion. For example, some people may be fearful of losing their job if they are too open about their concerns. Others may view reviews as tests. That is, it is highly recommended not to underestimate the level of threat or assume the meaning people attribute to undertaking these new roles.

7. It is recommended that further research be undertaken to further develop the CEO-MHS 26. The instrument is a major progressive step and goes beyond standard consumer satisfaction surveys by addressing things that matter to them.

Procedural

8. Need clarity from consumers about their wishes regarding involvement in the project should they experience exacerbation of their mental health problems. Specifically, does a family member/health professional have the right to call the team and request the consumer no longer be involved in the project? How is this handled? Maybe the consumer researcher needs to leave instructions with the project officer or other member of the team about contacting them personally or nominating a contact person.

9. Need detailed descriptions of the work required of consumer researchers i.e. attention needs to be paid to role clarity for all members of the team. These are new roles and new ways of working that require attention. People need to have detailed descriptions of the work required of them and what is expected.

10. Need to be clear about responsibility and accountability. One important such issue is contact with the project team (eg return of phone calls). Following up people can be a problem and this needs to be addressed.

11. The timeframe needs to be realistic. Casually employed consumers have lives outside the project. Work and other commitments do make the smooth running of the project difficult. Yet as the consumers are only casual employees it is unreasonable to expect them to drop everything when data collection has been finally organised. Allow extra time for the training and support etc for those people who cannot make scheduled days.

12. The project aimed to train up many consumers so they would be a resource for mental health services in this case the IAHS. Whilst this is essential, in terms of the project employment of one or two consumers on a more permanent basis may have been more useful. Perhaps the training of consumers in research needs to be viewed as a developmental process.

13. Clearly outline and discuss terms and conditions of employment eg travel time, payments (what is and is not included).

14. Some staff within the mental health service used “duty of care” to not allow consumer researchers to administer questionnaires to other consumers in private. This appeared to be an individual variable and occurred regardless of the number of attempts to redress the problem in some areas. Whilst this is probably to be expected, it may be overcome by more thorough training workshops with role reversal.

15. Attention needs to be paid to the practical details of organising consumer researchers getting to where they need to be. Many consumer researchers do not have access to private transport, a commodity most people take for granted. Reliance on public transport can severely hinder the effective functioning of the project and add considerable time to organisation.

16. Access to resources to support consumer researchers (eg library, email) can be difficult. Need to consider office space for consumer researchers and this would occur if the recommendation of regular part-time positions in preference to casual positions is taken into consideration.

SECTION 1:

INTRODUCTION

The overall aim of this project was to develop a consumer driven and directed method of evaluating mental health services to lead to their improvement. Such an approach demonstrates the credibility of consumers, a largely untapped resource within the mental health system. The difference between this project and most other projects is consumers were not only employed and trained as researchers and collaborators, they actively drove the development of the Evaluation Framework that has been one of the major outputs from this project. Involvement of mental health consumers in this way is unique. It takes consumer involvement in research to the next step of involvement in mental health system evaluation.

In essence the project privileged the knowledge that comes from the personal experience of serious mental illness and aimed to demonstrate how consumers could use this knowledge to conduct evaluative research in mental health. To achieve this aim the project had as its foundation the values, beliefs and principles that underpin *genuine* participation and partnership in any endeavour and these will be elaborated on here. To date, whilst partnership and participation with consumers is not only advocated but mandated in service planning and evaluation both in Australia and internationally (Commonwealth of Australia, 1997; Department of Health, London, 1999; US Department of Health and Human Services, 2001), such endeavours are occurring slowly and there are few examples of collaboration actually happening (Malins, Oades & Viney, 2003). This project is another step towards filling this void.

Definition of terms

Consumer

There are a number of terms used to describe a person who has the lived experience of mental health problems who may or may not have used mental health services. In the United Kingdom literature the preferred term is service ‘user’ or ‘survivor’, and describes someone who use or have used mental health services. In the United States of America it appears dependant who is using the term. ‘Survivor’ is a popular choice for people who have had particularly bad experiences of the mental health system and the term ‘ex-patient’ is also used. Patient and client are used infrequently. In Australia the term consumer is currently the preferred term for someone who has the lived experience of mental health problems serious enough to warrant the intervention of a mental health professional and includes people who have had both positive and negative experience of the mental health system.

Consumer Researcher

The position title the consumers who were employed as researchers on this project chose to identify them was Consumer Researcher (CR).

Mental Illness

There was a debate about the term to describe a person's experience and behaviour that would attract a psychiatric diagnosis. Terms such as 'mental health problems', 'mental distress' and 'mental illness' are often used. The consumers in this project preferred the term mental illness to denote the seriousness of their symptoms and the major impact these have on their lives and it is the term used in this report.

Evaluation

The project team's understanding of evaluation that underpins the development of the CEO-MHS Evaluation Framework is that evaluation includes: measurement, or systematic data collection; description; judgement; an attempt to create or implement change based on this judgement; and that evaluation in itself is a political activity.

Historical Context of the Project

Over the past couple of decades mental health services have reorientated their thinking about what is important in service provision. Rather than focusing on organization and financing of services to improve outcome, there is a realisation that the most important issue facing them is whether the care they offer actually works (Walshe & Ham, 1997).

There are a number of reasons for this shift but historically the catalyst was The Alma-Ata Declaration on primary health care built on the principles of equity and justice (World Health Organisation, 1978). The declaration enshrined universal access to resources in addition to moving towards people becoming more self-reliant and able to exercise control over their own health. Promoting health in this way enabled people and their families to actively participate in illness prevention, its management and outcome whilst at the same time stimulating the informed consent and consumer movements (Stanton & Tooth, 2004). Consequently consumers became more informed about their choices, the risks and benefits of the interventions and services with which they were provided and searched for meaningful interactions with service providers (Gallant, Beaulieu & Carnevale, 2002). As these authors note, this paved the way for participation and relationships such as partnerships to promote the dynamic dialogue required for this changing focus in health care, whilst at the same time reducing the inequities between participant groups.

The concepts of partnerships, participation and empowerment are inextricably linked. A partnership between different service providers or other stakeholder groups as well as between service provider and service recipients invites participation that hopefully leads to empowerment, not just for consumers but for all concerned.

People's participation in mental health care occurs individually at a therapeutic level and collectively at a systems level. Participation at an individual level can be either passive or active (Townsend, 1998) and there is the tension between the two. Passive participation in research occurs when people are either administered predetermined questionnaires or asked to be on the research team but have no real ability to influence the research process. Whereas active participation occurs when people are facilitated, guided, encouraged or supported to be fully involved and actively drive every step of the research process. This understanding of active participation provided the foundation for the process undertaken in this project.

At a systems level, in the Western world at least, policy and planning documents for mental health services mandate participation and partnership with mental health consumers as well as other stakeholders in various aspects of the mental health system. This change has occurred because it was argued consumers and carers are more in tune with consumer needs than are trained health professionals (Townsend, 1998) because their experience of living with their particular problems and use of mental health services provides insight into useful research questions and how these should be framed (Goodare & Lockwood, 1999; Liberati, 1997). In Australia it has long been recognised that consumer participation should be linked to issues of quality and improvement in services (Wadsworth & Epstein, 1996). Wadsworth further asserts, “Evaluation is for those whose unmet needs provide the benchmark and driving values for checking whether a service, campaign or activity works.” (1997, p2).

Hence the paradigm change resulted in a shift away from a primary focus on the expert knowledge of mental health professionals to the expert knowledge that comes from the lived experience of serious mental illness. A number of authors (Deane, 1987; Gill, Pratt & Librera, 1998; NSW Health, 1999; Perkins, 2001; Rapp, Shera & Kisthardt, 1993) have recognised the differing perspectives consumers bring to evaluation of services compared with mental health professionals and/or external evaluators.

Mental health policies and plans have acknowledged the centrality of mental health consumers in a range of roles and in a number of activities undertaken within mental health services for at least the last decade. However, it is surprising there is such a dearth of information on how this has been undertaken and processes and outcomes described and discussed. Those of us who have been in one of the stakeholder groups, and involved in mental health services for a number of years, are aware of the inherent challenges to genuine participation and partnership that are often undermined and result in tokenism and disempowerment. Rapp, Shera & Kisthardt (1993) support this position. Liberati (1997) believes there is still a power imbalance that underlies the discrepancies found between rhetoric and practice in this area even amongst progressive professionals that is displayed through paternalistic attitudes and a belief that consumers lack the knowledge and skills to participate. More radically Emerick (1996) speaks of the need for “mad liberation” to overcome the almost universal invalidation of the views of mental health consumers.

The most common form of consumer disempowerment occurs when there is a failure to hear people’s stories of their experiences and their problems (Barker, 2001). When health professionals and researchers ask questions purely from a basis for him or her self in order to feel they have performed their professional duties then disempowerment is likely to result. Additional challenges to collaboration arise in relation to funding, and the differing roles of consumers and professionals. For example professional academics can focus on the research, whereas consumers often have other jobs as well as being involved in the research (Goodare & Lockwood, 1999).

From the inception of this project those involved have been mindful of potential barriers to genuine collaboration between all the stakeholders and the resulting concerns addressed within the research process.

Oades, Viney, Wong, Bowker & Strang (2000) suggest that appropriate research may provide a 'voice' for consumers in contrast to traditional research that can be exploitative of or irrelevant to mental health consumers. These authors describe a set of collaborative research approaches, that, if followed are no less rigorous than traditional quantitative and empirical approaches, yet are more appropriate for (a) allowing consumers to be heard and (b) generating beneficial change within the mental health service (Lord, Ochocka, Czarny, MacGillivary, 1998).

Evaluation in Mental Health Services

Despite some examples of productive consumer participation in mental health service evaluation such as Wadsworth and Epstein's (1996; 1998), and Lecomte, Wilde and Wallace's (1999) work, the actual implementation of methodologically sound initiatives where consumer criticisms are viewed as credible are still underdeveloped and many barriers remain. The majority of evaluations of mental health services are driven by approaches and methods that assume researchers to be the experts and consumers to have little to offer (Oades et al., 2000). These authors argue that consumers have considerable expertise and are capable of selecting research questions and methods as well as collecting the relevant information themselves. However Byas et al., (2002, p75) concludes "it has been a rare phenomenon for consumers to be actively involved in mental health research and evaluation beyond the role of research subject," and Malins (in preparation) believes this is due to the paternalism discussed above. Therefore the consumer-directed approach to research and evaluating mental health services, reported on here, is critical.

Evaluation therefore needs to be participatory and collaborative such as Responsive Constructivist Evaluation (Guba & Lincoln, 1989), Empowerment Evaluation (Fetteman, 1996) and Utilisation-Focused Evaluation (Patton, 1990). The important facets of these styles of evaluation have been summarised by Malins, Oades & Viney (2003) as follows:

- Evaluation process involves participants in learning evaluation logic and skills
- Constructivist assumptions that it is not just the entity being evaluated that is relevant but the participant's views of it
- Participants own the evaluation, they make major focus and design decisions, they use and apply findings
- Process of the evaluation is as important as the outcome
- Participants focus evaluation on processes and outcomes they consider important, and to which they are committed
- Can make use of external facilitator/evaluator – who's role is collaborator and learning resource
- Use of evaluation is vital, a belief that responsiveness of evaluation creates utility

The negation of true partnerships with consumers in research applies equally to evaluation. Similar to research, professionals' perspectives have driven mental health service evaluation (Campbell, 1997; Prince & Prince, 2001). This is in spite of marked differences between professionals and consumers in what they consider important in evaluation (Gill, Pratt, & Librera, 1998; Perkins, 2001). As Perkins (2001) notes, we have to address the questions of whose views are valid in understanding effectiveness of service provision and who has the right to determine what consumers need. Such a view takes evaluation away from what Clarke (2000) identifies as the now routine use of consumer satisfaction surveys as a method of information gathering for quality assurance purposes. Consumer satisfaction surveys are commonly used in mental health as a means of evaluating service outcomes (Williams & Wilkinson, 1995), however their usefulness is limited.

Limitations of consumer satisfaction surveys

A consumer satisfaction survey as a method of evaluating mental health service provision has many difficulties. A common belief exists that mental health consumers' interpretations of their own circumstances, including their evaluation of services provided, are meaningless manifestations of psychotic processes (Hatfield & Lefley, 1993; Sayre, 2000). The medical model may describe dissatisfaction with services as a symptom of mental illness, undermining all credibility of claims. To address this it has been suggested that customer satisfaction surveys may be useful for mental health services (Donabedian, 1992; Salzer, 1997).

Yet evidence suggests (Williams & Wilkinson, 1995; Avis, Bond & Arthur, 1997) the assumption that people have prior expectations against which to judge the care they receive is too simplistic. Research findings (Williams & Wilkinson, 1995; Avis, Bond & Arthur, 1997) has identified that the nature of the encounter the person had with the service to be more indicative of satisfaction. In addition the authors found people's evaluation of services varied over time and encounters, leading them to conclude such surveys are obtaining only one moment in a series of care encounters. Therefore these authors advocate qualitative approaches to consumer evaluation to overcome these limitations.

Consumers typically do not develop satisfaction surveys (Entwhistle, 1997; Gill, Pratt, & Librera, 1998). Campbell (1997) criticises satisfaction surveys developed by professionals because they are more likely to measure what is of concern to them rather than to the consumer. This difference of opinion about what is important in research has been well documented by others (Tooth, Kalyanasundaram & Glover, 1997). There is also reluctance by professionals to ask questions that will identify dissatisfaction (Campbell, 1997) leading to disagreement about what constitutes a desirable outcome. Perkins (2001) concludes the only way to reflect consumer concerns is for them to develop the measure.

Satisfaction surveys developed from a consumer base (Hansburg et al., 1996) have found lower levels of satisfaction than that reported in other studies. Hansburg et al (1996) believe one reason for this finding could be the consumer administration of the survey allowed respondents to be freer in their expression of satisfaction. In contrast, Clark, Scott, Boydell & Goering, (1999) found higher levels of satisfaction than anecdotal evidence suggests when consumers administer surveys developed without consumer input. These authors also found high levels of satisfaction regardless of whether the survey was administered by staff versus consumer interviewers. Polowczyk et al (1993) report similar findings. However Clark et al (1999) note the consumers in this study were frequent users of the services and the more dissatisfied people may no longer receive services. Clark et al (1999) conclude that whilst consumers may have been satisfied with the services they received, they may have been hesitant to disclose their true feelings because of their dependence on the system and for reasons of social desirability. Gill, Pratt & Librera (1998), whilst concluding social desirability and ingratiation may have been a factor in their study, also found this existed for both staff and consumer administered satisfaction measures.

Malins (in preparation) concludes there are a number of contributing factors to consumer responses on satisfaction surveys. These include:

- Lower satisfaction is likely when instruments focus on issues relevant to consumers
- Responses can vary depending on the involvement of consumers in the service leading to directional bias
- Responses are likely to vary according to how empowered the consumers feel
- Increased feelings of empowerment appear to relate to lower levels of satisfaction and vice versa
- There is a possible interviewer effect when a consumer is dissatisfied with an aspect of the service
- To ensure valid feedback from consumers about the services they receive they must be able to address issues with other consumers in privacy

The fragmented use of evaluation methods, rather than using comprehensive conceptual models of evaluation in mental health services has been severely criticised (Milne, 1987). For him, evaluation needs to indicate areas within the services that need change and provide helpful information. Tools such as satisfaction surveys do not achieve this aim. Rapp, Shera & Kisthardt (1993) argue for the collaborative development between consumers and professionals of new instruments to ensure both language and issues relevant to consumers are measured. The current focus on outcome measures suffers the same critique as satisfaction surveys (Malins, in preparation). Therefore it is reasonable to conclude that it is time to develop alternate models of Mental Health Service Evaluation.

Models of mental health service evaluation involving consumer participation

Malins (in preparation) has noted the limited application of modern evaluation theory to mental health evaluation. Whilst a considerable amount of evaluation research has been conducted in mental health there is typically a gap between theory and practice (Kirkhart & Morgan, 1988). These authors report evaluations frequently lack grounding in a conceptual model, whilst conceptual models have been proposed with no link to empirical evidence.

However as Malins (in preparation) notes, despite the criticisms above, there are some excellent examples in the literature of models and methods of evaluation for mental health services have been adopted, and/or developed. These include the: User Focused Monitoring (UFM) (Rose, 2001); Project Eve (Fox, McDermott, Hamilton & Toumbourou, 1996); and development of the CUES-U instrument (Lelliot, et al., 2001). UFM was developed by the Sainsbury Centre for Mental Health with the aim to “evaluate mental health provision from the perspectives of service users with severe and enduring mental health problems” (Rose, 2001, p12). This model used local consumers as the project team and they developed the questionnaires, collected the data and had a role in data analysis. Project Eve (Fox et al., 1996) was a collaborative model of evaluation involving consumers. It developed and tested outcomes relevant to local conditions, included a variety of stakeholders working collaboratively, but service professionals developed the model of evaluation. London’s Department of Health aimed to evaluate the mental health services against the aspirations and experience of its consumers. This resulted in the development of the CUES-U, a brief self-assessment instrument. However, these examples demonstrate varying degrees of consumer involvement and are more accounts of evaluations conducted within services. Malins (in preparation) asserts there is limited rigorous based work and when it is undertaken it is only on a small scale and not easily replicable (e.g., Boll's (1995) evaluation of Laurel House).

Consumer driven and directed research

Hunt (1997) provides a concise overview of consumer health research that she describes as "research conducted by and with consumers" as opposed to "research conducted on behalf of consumers" (p.48). According to Hunt (1997) research is consumer driven and directed if the following points are taken into consideration:

- Consumers control the research process
- The research is focused on finding and using appropriate research methods to elicit information relevant to consumers
- The research creates a genuine consumer voice in research that is proactive rather than reactive
- Consumer health research creates different knowledge by capturing diverse and complex perspectives
- The broader range of views about health and health care creates the opportunity to affect policy development
- The research project creates education opportunities for the consumers to be involved in the research process
- A high level of consumer involvement demonstrates how the issues of control, power and professional involvement are resolved
- The relationships of professional as researcher and consumer as research subject do not exist

Other researchers support these points. For example Ochacka, Janzen & Nelson (2002) identify consumer involvement in research provides a power base from which they can negotiate and act and thereby redress traditional power imbalances by giving them a voice in the decision making process. Rapp et al (1993) assert that consumers be involved in framing the entire research process. Linhorst & Eckert (2002) make additional important points for consideration in consumer involvement in research that have not been considered thus far.

- It is consumers' right as a major stakeholder
- It is consistent with numerous models of evaluation (e.g., Participatory action research (PAR), empowerment evaluation, and utilisation-focused evaluation)
- Participation benefits consumers

A number of authors have identified the positive outcomes for consumers who participate in research (Lammers & Happell, 2003; Simpson & House, 2002). Others (Tobin, Chen & Leathley, 2002) have reported on the diversity of consumers and their varying levels of interest and ability to be involved. In this study the major barrier to participation was the attitudes of service professionals. However there is still limited knowledge of the implications of having consumers fully involved in research (Ochocka et al., 2002). For these authors the value driven strategies of empowerment, social support, "learning as we go" and social justice are necessary to reduce the power differentials in collaborative research.

The project used the above points to guide the research process and the PhD student attached to the project focused on consumers' experiences of being involved in this type of research as the topic for her PhD thesis (Malins, in preparation). Other than for the initial training (that is discussed in detail in Chapter 2) the consumer researchers (CRs) were able to choose the aspects of the project they wished to be involved in, rather than this being decided by academic researchers or the project team. This is described in greater detail in Chapter 3, the method section of this report. The CEO-MHS Evaluation Framework and the other outputs from the project are presented in Chapter 4.

SECTION 2:

TRAINING MENTAL HEALTH CONSUMERS AS RESEARCHERS

The training of the mental health consumers to become researchers for this project was the subject of Rebecca McLeod's Master's thesis in Clinical Psychology. Therefore at the beginning of this project Rebecca had a significant role, together with the research team, in this important part of the research. The Training Manual developed out of the project is in Appendix 1. The following provides a background to this part of the project.

To ensure successful consumer participation in the research process requires adequate education and training. Whilst consumers benefit from being involved in the research process (Wilson et al., 1990; Morell-Bellai, 1994; Epstein & Shaw; 1997), little has been documented on how to train consumers in research skills. Most published papers provide only brief descriptions of training and do not identify the models on which the training process was based (McLeod, 2002). Therefore without a model, the underlying assumptions of the training process cannot be identified or replicated (Bramley, 1991).

Effective learning is dependent upon the learners' needs (Bramley, 1991) and understanding how each individual construes the phenomenon of learning (Beail, 1985; Fromm, 1993). The development of the training program stemmed from these two points to ensure it was effective. In addition, the training program had to take into account the neuropsychological and cognitive deficits some mental health consumer's experience.

Development of the training program

The learning needs of fourteen CRs were determined using a focus group. The group took 40 minutes and was videorecorded (with permission) to allow analysis of the information. The focus group provided a forum for the trainer to begin to understand the consumer's perspectives, as well as providing a "warm-up" for the consumers and help them to get to know one another. To make the focus group as non-threatening as possible, consumers were able to present much of the information in the third person. Questions were asked about their experiences of being research participants, their existing skills and qualities they felt they could offer and about any personal needs to be considered during training. Twelve of the fourteen CRs contributed to the discussion.

McLeod (2002) developed a pre and post-test design to measure whether the CRs perception of research altered as a result of the training program. The "Lets Just Say" technique (Epting, Probert & Pittman, 1993) was used for this purpose. However, rather than using group methodology, one on one interviews were conducted with the CRs. The post-test interview was built into the training program by having the CRs interview one another. This provided the dual opportunity for them to practice their newly acquired skills and for their skill level to be assessed. The following 4 questions were asked to gain an understanding of their perceptions about research. The questions were:

1. Can you tell me what the term research means to you?
2. Let's just say you're a researcher. What sorts of things would you do?

3. Let’s just say you’re a good researcher. What are the things that make you a good researcher?
4. Let’s just say you’re a bad researcher. What are the things that make you a bad researcher?

Identified Training needs

The above processes identified the CRs’ formal and informal training needs. At a practical level they identified the following needs in relation to their role as researchers:

a) Practical research skills

The majority of CRs stated they needed to learn how to conduct interviews, run discussion groups, ask questions, carry out analysis, work equipment, develop hypotheses and goals and understand research terminology.

b) Communication and interpersonal skills

Specific communication and interpersonal skills were identified by two thirds of the participants. These included learning how to introduce themselves, how to make the person they interviewing comfortable and correct listening skills.

c) Development of objectivity

In terms of interpreting research data and their interactions with people, three quarters of the CRs wanted to learn how to be objective, rational, open-mined and aware of their own biases. A quarter of the CRs also wanted to learn about the rights of research participants, particularly in terms of confidentiality and informed consent.

d) Establishing boundaries

Interestingly most of the CRs wanted to learn about appropriate levels of self-disclosure and how to separate themselves emotionally and a quarter wanted clear direction of what to do in threatening situations. This is similar to Morell-Bellai & Boydell’s (1994) study in which consumers wanted training in dealing with uncooperative people and people with different personalities.

e) Informal training atmosphere

Half of the CRs wanted a relaxed and informal training environment where they would not feel like students. To achieve this, the training took place in a variety of settings including the tearoom and outside on the lawn. Other strategies such as moving around to break the monotony and splitting them into smaller groups also facilitated this process.

f) Frequent breaks

Difficulties in concentrating for long periods prompted just over half of the CRs to cite the need for frequent breaks throughout the training. Difficulty in concentrating due to cognitive deficits resulting from some mental health distress has been reported by others (Gourovitch & Goldberg, cited in Pantelis et al., 1996).

g) Feedback, positive reinforcement and support

Half of the CRs actually reported on the need to receive positive reinforcement during training. Specifically, when needing correction, CRs wanted this information presented in a positive rather than negative way so they would keep a keep a positive outlook on the project and they didn't want to be made to feel inadequate. Again, similar findings have been reported by Morell-Bellai & Boyden (1994).

The Training Program

The three-day training program was based on 1) the skills they needed specific to the CEO-MHS project (conducting interviews and focus groups, ethical considerations and the giving and receiving of support) and 2) the findings from the "Let's Just Say" interviews and focus group used in the current study. Honey & Mumfords' approach to learning that is practically derived from Kolb's learning cycle (Bramley, 1991) provided the framework for the training program. The essence of their approach is acknowledging people learn in different ways and for different reasons and for training to be effective these points must be recognised and programs adjusted accordingly.

A training manual (Malins, Morland & Oades, 2002) was produced as a result of this part of the project and is included in Appendix 1. It is the intention of the project team to further develop this manual and make it an independent publication.

Consumers' experience of the training program

The CRs had a somewhat stereotypical understanding of research prior to the commencement of the training program. However for most the training increased their knowledge of research skills, specifically in relation to conducting interviews and focus groups. The latter was the most difficult aspect of the training for nearly half of the CRs due to the need to have the ability to focus on more than one task at a time and remembering all of the information to provide a summary at the end.

In terms of the organisation and structure of the training program, more than half the CRs found the program casual, easy to follow and comprehensive. In retrospect the same number of CRs would have liked shorter training periods over a longer period of time to enable them to practice what they had learnt.

The training program increased feelings of self worth for half of the CRs. The program increased their self-confidence, feelings of value because they felt positive about being able to make a worthwhile contribution. It was important for some to have gained skills to include on their CV with the hope of improving their employment prospects.

SECTION 3:

METHODOLOGY

The research was significant and innovative because it redressed the power imbalance between professionals and expert researchers with the group of mental health consumers. The project was undertaken in the Illawarra region of NSW, Australia. Wollongong, the regions largest city, is 80 kilometres south of Sydney. A demographic study at the beginning of the decade (McDonald & Wilson, 1991) showed the Illawarra had high divorce and crime rates, as well high use of analgesics and low incomes. Today, such a study would show high unemployment and suicide rates as well, all being linked to high rates of mental health problems and disempowerment (Wilkinson, 1997). Therefore this project was of particular benefit to this region.

The regions for data collection were Area A (Northern), Area B (Southern) and Area C (Shoalhaven). These regions have socio-economic differences that provide useful information about differences in consumer views of mental health services and add to the generalisation of the model.

The Project Aims and Objectives

The project aims were to:

(a) Improve mental health services by making credible and empowering their consumers.
(b) Demonstrate the, as yet, untapped resource of consumers as mental health researchers and the implication of this resource to health service evaluation.

The project objectives were to:

(a) Develop a consumer-directed model to evaluate mental health services.
(b) Develop consumer-directed quantitative instruments to evaluate mental health services.
(c) Utilise genuine collaboration between experienced researchers and mental health consumers to improve the validity of the data generated.
(d) Apply the model and evaluate the local area mental health service to test its utility.
(e) Provide a statement of consumer visions of future mental health services.
(f) Develop practice manuals for the training of mental health consumers in research.
(g) Provide internationally competitive publications documenting the various stages and components of the project.
(h) Develop locally a team of consumers trained in research skills.
(h) Develop locally a team of staff more aware of consumer views and capable of working with consumer researchers.

Research Methodology

The research design and methodology differed from evaluation that focuses on standard customer satisfaction surveys of mental health services in three major ways. First, the research began with a comprehensive qualitative data collection phase that allowed for the development of the quantitative data. Second, to increase the robustness of the qualitative data collection, focus groups were used in the formative phases of the research. Third, and most importantly, mental health consumers were used exclusively at all times for data collection and they drove the development of the Evaluation Framework. Appendix 1 involves a graphic depiction of the project. A timeline of the project milestones appears in Appendix 2. In keeping with good evaluative practice the Mental Health Service, other consumers and the local community were kept informed about the project's outcomes using a variety of methods. These included a range of media communications, consumer newsletters and presentations about the project to the Mental Health Service.

CEO-MHS 26 and Evaluation Framework Development

The first stage of the research design involved the development of the CEO-MHS Evaluation Model. The aim of this stage of the project was to: (a) compile comprehensive qualitative data on what consumers see as important aspects of mental health services (b) develop a model and instruments, using this qualitative data.

Qualitative data collection

This phase of the project involved a number of sequential parts. First the consumer researchers (CRs) were recruited then trained in the research skills specific for this project. The CRs' first task was to conduct consumer focus groups to determine the development of the interview schedule. Next one-to-one interviews were conducted with other consumers to collect data to inform the development of the questionnaire. Each of these is now discussed.

Recruitment of Consumer Research Assistants

At the beginning of the project fourteen (7 males and 7 females) Consumer Research Assistants were employed. The selection criteria are in Appendix 3. Consumer researchers were recruited via the Consumer Initiative Coordinators of the Illawarra Area Health Service (IAHS: the Associate Investigators of the project). They were recruited from the Illawarra and Shoalhaven region of NSW Australia and employed as casual research assistants by the University of Wollongong. The project had allowed for 8 consumers to each be employed for 35 hours for each of the three years of the project. However it was decided to increase the number of CRs from 8 to 14 to account for natural attrition and to ensure adequate availability should any of the CRs experience an exacerbation of their mental illness. This decision proved fortuitous. All of the CRs had direct experience of mental/emotional illness and had used an area mental health service. One third of the applicants had tertiary qualifications. They participated in a training program in research skills, specific to the CEO-MHS project.

Training Consumer's as Research Assistants

The CRs determined their training needs in a focus group. A three-day training program that included interviewing skills, conducting focus groups and ethical issues such as confidentiality resulted. This training has already been fully outlined in Chapter 2. All CRs received ongoing supervision and support throughout the project. Moreover, training and use of a significant number of consumer researchers in this project is better than previous research because: (a) it builds capacity for future consumer research, (b) it provides greater collaboration and a team, rather than a small number of 'expert researchers', and (c) it guards against problems due to consumer researchers not wishing to continue.

In addition the CRs regularly met with Gillian Malins, the PhD student, for debriefing of the project. Consistent with the values of the project team, the CRs were able to choose the activities they wished to be involved in during the project (with the exception of the training component). The activities available to the CRs appear in Table 1.

Table 1: Research activities Consumer Researchers (CRs) in the CEO-MHS team could have been involved in, and corresponding stage in the research project (Source: Malins, in preparation).

Training	3-day training session and orientation, 2001 Further training in conducting interviews, 2002 Training in evaluation theory and methods, 2002/2003
Planning and designing research method	Development of Focus Group questions/guide, 2001 Development of Interview questions/guide, 2002 Making sampling decisions for interviews, 2002 Planning feedback sessions for participants, 2003
Conducting data collection	Facilitating focus groups with consumers of mental health services, 2001/2002 Conducting interviews with consumers of mental health services, 2002/2003 Quantitative survey piloting with consumers of mental health services, 2003
Data interpretation/analysis	Interpretation and validation of meanings in focus group transcripts, and coding of data Interpretation and analysis of interview data.
Dissemination	TheMHS conference presentation, 2002 TheMHS conference presentation, 2003 TheMHS conference workshop facilitation 2004 Feedback presentations to participants from focus groups and interviews, 2003 Writing journal articles with team, 2003, 2004
Original work	Development of CEO-MHS Evaluation Framework, 2003 Development of CEO-MHS Questionnaire, 2003

Focus Groups

CRs facilitated focus groups in 2001. A focus group, as the name infers, is a focused discussion amongst a group of people with specific information or "expertise" are brought together to talk about a specific topic in an organised manner (Phan & Fitzgerald, 1996). The general research question for the focus groups in Stage 1 was: *What criteria would consumers use to evaluate mental* *health services?* The focus groups were run in locations convenient to the participants. The specific focus group questions included the following.

- *What have been your experiences of Mental Health Services, the good and the bad?*
- *What needs do you think a Mental Health Service should meet?*
- *How do you think the Mental Health Services, and the service you receive (or have received), could be improved?*
- *I'm wondering what questions you would like to be asked about the Mental Health Service?*

Participants were also introduced to the National Standards for Mental Health Services and asked the following question.

- These are some areas people have found important to them. What do you think?

Questions like these generated qualitative data from 20 volunteer participants, from the three regions within the IAHS, on evaluation of the mental health service. These qualitative data, while important in themselves, were not only used for generation of the instrument in Stage 2 of the research design but the information was used for the development of the evaluation framework.

The demographic data for the focus group participants appear in the following tables. Table 2 contains the employment status (10% did not respond to this question) and Table 3 details income range (25% chose not to respond to this question). Table 4 contains information on the type of admissions the 60% of participants who responded positively to this question had had to psychiatric facilities. Twenty five percent reported no admissions to inpatient facilities whilst 15% chose not to answer this question. Table 5 reports on the participant's diagnosis, however 30% of participants chose not to answer this question.

Table 2: Employment status of focus group participants (n=18)

Employment Status	Percentage
Full-time	11%
Part-time	17%
Casual	6%
Unemployed	44%
Not in work force/retired	22%

Table 3: Income range of focus group participants (n=15)

Income Range	Percentage
$0-9,999	53%
$10,000 – 19,999	33%
$20,000 – 29,999	7%
$30,000 – 39,999	0%
$40,000+	7%

Table 4: Type of admissions to psychiatric ward of focus group participants (n=11)

Status	Percentage
Voluntary patient	45%
Involuntary patient	27.5%
Experienced both	27.5%

Table 5: Reported diagnosis of focus group participants (n=14)

Diagnosis	Percentage
Schizophrenia	36%
Depression & acute anxiety/stress	22%
Major depression	14%
Bipolar disorder	14%
Psychosis due to organic brain disorder	7%
Have not been informed	7%

Focus group data analysis and verification

The focus groups were audio taped and transcribed. Qualitative data analysis was most appropriate given the aim of the project was to understand consumer's perspectives of mental health services. The Interpretative Phenomenological Analysis method (IPA) (Smith, Jarman & Osborn, 1999) was chosen because of its focus on meaning whilst at the same time acknowledging the interpretive nature of analysis. Rather than focusing on a fixed protocol Smith et al., recommend four sequential steps. These steps are outlined in Table 6.

The IPA method of analysis of the focus group data, similar to most qualitative data analyses, involved researchers working in teams of researchers and consumers, reading and re-reading transcripts, formulating agreed themes, and assessing the quality of the analysis using criteria outlined by Miles & Huberman (1994), including confirmability, dependability, authenticity, transferability and importantly to consumers the utilisation, application and action orientation of the data generated. At all times consumer researchers worked in pairs so they could support one another.

Table 6. Methodology for focus group data analysis

Step 1	Close reading of each transcript with note taking regarding consumers perceptions of Mental Health Services.
Step 2	Broad labels applied to themes in each focus group transcript and list of emerging themes developed.
Step 3	Themes across focus groups compared and master list of themes developed.
Step 4	All focus group transcripts coded using master list.

The themes were verified at two levels. First, the PhD student analysed the resulting themes to ensure the interpretations made captured the participants meaning. Once this had taken place the external consumer consultant and two CRs were provided with the complete transcripts of the focus groups, the labels and explanations of the themes as well as the following questions to answer:

1. How does this analysis fit with your understanding of the discussions represented in the transcripts?
2. How adequately does this analysis capture overall the meanings expressed in the focus group discussions?
3. What has been missed in this analysis?
4. What has been included that you would delete from the analysis?
5. Do the labels used fit the data? Do they capture the themes adequately?
6. Would you use different labels to discuss these themes? If yes, what would your labels be?
7. What other comments do you have – about the data or the analysis?

Changes were then made to the analysis, based on the feedback provided by the external consumer consultant, and the two CRs. A total of 8 themes were agreed upon. The identified themes appear in Table 7.

Table 7: Themes from focus groups on consumer evaluation of service provision

Identified theme	
1	Valuing/Devaluing of the person
2	Quality and completeness of care
3	With/Without resources
4	Involvement/Lack of involvement
5	Availability/Inadequacy of information and education
6	Positive and negative aspects of medication
7	Isolation and Community
8	Power and Disempowerment.

The second level of validation required specific segments of the transcripts being coded by several people (the PhD student and two consumer team members involved in the first level) to ensure the themes were being consistently applied to the transcripts. The team members each coded sections of text, using the themes from the analysis. The application of themes could then be compared across three coders. To ensure the power in interpretation of the text did not reside with the non-consumer PhD student coder a two-thirds agreement method was used. This meant that when any two of the three researchers agreed on a code for the specific text, that interpretation was adopted. Strong agreement between at least two of the three coders was found for the themes in each focus group.

Interview methodology

The themes from the analysis of the focus groups were used to develop the interview questions. Two groups of CRs, working independently, drafted proposed interview questions. Several meetings including consumer and academic researchers were then held to discuss the proposals and negotiate the questions to be used in the interviews and interview format. The resulting interview schedule consisted of eight questions (see Appendix 4). The first two questions were broad and open-ended inviting participants to discuss their general views of mental health services. The other six questions related to issues identified in the focus groups. The CRs conducted the individual interviews with the consumer interview participants.

Given the qualitative nature of the interviews and our aims, purposive sampling was used to select interview participants. Purposive selections of participants recognises the goal of attempting to understand in comparison to the goal of generalisation that is common to quantitative research (Maykut & Morehouse, 1994). Specifically the technique of Maximum Variation Sampling was used. This strategy ensures the people selected represent the greatest differences in the phenomenon being studied. The goal of this method is to sample a range of experiences of the phenomena of interest. Maximum variation sampling involves using a working knowledge of the context to build the sample. Therefore, sample development changes as your sample does, which means that as interviews are occurring these may inform who you sample next. The literature and/or experts inform the initial sampling decisions and are guided by the questions “what are the important variables that may affect experience of the phenomena and which of these variables will provide maximum variation?” (Maykut & Morehouse, 1994). This sampling method is used in projects involving sample sizes such as those occurring in qualitative research.

The interviews were carried out in three phases with analysis and validation of the data between each phase allowing further sampling decisions to be made. In Phase 1 a team consisting of the Consumer Research Team, Management Committee members and the external consultants to the team, determined the sampling.

First, the variables relevant to the project were brainstormed using the prompt question “what are the important variables that may affect people’s experience of public Mental Health Services?” Miles & Huberman (1994) advocate the consideration of the setting, actors and events to understand the important variables. Specifically for this project we considered the Mental Health Service environments, the way in which consumers vary and the things that happen for consumers when they have contact with the Mental Health Service.

Second, the list was considered and decisions were made about which variables would provide the maximum contrast for the purpose of the project. This process produced a sampling profile or matrix that was used to identify participants. Recruitment was then targeted to reach participants who fitted this profile. Using this method 33 people, 14 males and 19 females were interviewed, ranging in age from 20 to 67 years with a mean age of 43 years. The participants had utilised a broad range and types of service in the range of treatment settings and were drawn from Wollongong (regional), Shoalhaven (rural), Sydney (metropolitan), Orange (rural), Parkes (rural) and Condobolin (rural). Table 8 details the participant’s country of Origin. Eight participants worked in the mental health area, 9 were highly experienced consumer representatives and 20 rated themselves as highly experienced users of the public Mental Health Services.

Table 8: **Interview participants country of origin (n=33)**

Country of birth	No. of participants
Australia	26
Yugoslavia	2
Norway	1
Macedonia	2
Vietnam	1
Turkey	1

In total, 15 participants reported being voluntary patients when hospitalized, eight reported experiencing involuntary hospitalization, while a further eight participants reported experiencing both at various times and 1 participant chose not to answer this question.

Participants' reported diagnosis was not a sampling category however this information appears in Table 9. Two participants did not respond to this question. Similarly, employment status and income range were not linked to our sampling strategy, however these data are summarized in Table 10, and Table 11 respectively.

Table 9: **Reported diagnoses of participants (n=31)**

Diagnosis	Percentage
Schizophrenia	42%
Major depression	6.5%
Bipolar disorder	25.8%
Acute anxiety disorder, endogenous depression	3.2%
Bipolar, brain injury, personality disorder	3.2%
Depression/bipolar	3.2%
Chronic anxiety, depression, OCD	3.2%
Depression, schizophrenia, OCD, anxiety	3.2%
OCD and depression	3.2%
Have not been informed	3.2%

Table 10: Employment status of participants (n=31)

Employment Status	Percentage
Full-time	9.7%
Part-time	29%
Casual	0%
Unemployed	32.3%
Not in work force/retired	29%

Table 11: Income range of participants (n=24)

Income Range	Percentage
$0-9,999	54.2%
$10,000 – 19,999	33.3%
$20,000 – 29,999	4.2%
$30,000 – 39,999	0%
$40,000+	8.3%

Interview Data Analysis

The analysis, as with the focus group data, was grounded in Interpretative Phenomenology Analysis, a comprehensive process that focuses on personal meaning; is interpretative; and concerned with the participant’s perspective. The interview data was analysed using the same team (PhD student and 2 CRs) as the focus groups and followed the same 4-step process documented in Table 6. The CRs role in the interview data analysis built on the experience they gained in the focus group data analysis. This is consistent with the philosophy of the project and required additional training in the use of the Nvivo computer program and the IPA method of analysis.

The use of the purposive sampling method to obtain participants meant the interviewing occurred in two phases. As discussed earlier initial participants were chosen to provide maximum variation, however later sampling was based in interview data analysis. Normally one researcher undertakes this but, given the collaborative nature of the project, it was necessary to have at least two people, one a CR, involved in analysis of interview transcripts.

An analysis of transcripts occurred following the first interview phase. A list of initial themes was developed, compared, and discussed by the team including their impressions of the data gathered to date. This discussed yielded a broad range of themes and it was agreed by these interpreters that saturation was close to being reached. However, several themes emerged that the team thought required further information. Hence it was agreed more effort was required to target participants in the under 30-age range, and participants from a greater variety of cultural and linguistic backgrounds. This process formed the basis for selecting participants for the second phase of interviewing.

The final analysis of the interview data was conducted by one of the CRs and the PhD student. Using an adaptation of the IPA method for the larger number of transcripts, the CR analysed 75% of the interview transcripts and the PhD student analysed all of the transcripts. Agreement on the final interpretation was reached over a series of meetings. At these meetings congruent or overlapping interpretations, and differing analyses were discussed, reflected upon, and agreement reached on final interpretations. Eleven interview themes were identified and these were labelled as follows and used to develop the instrument (Malins, Viney & Oades, in preparation). The interview themes appear in Table 12.

To verify the above analysis feedback was sought from the interview participants. Four feedback sessions were conducted across NSW to ensure all participants could attend. All the participants attending the feedback sessions obtained a written summary of the analysis prior to attending the session. They were informed the purpose of the session was to check in the feedback sessions “did we get it right?” from their perspective. At the same time a broader presentation of the CEO-MHS project was made by a number of team members. Following the presentation and discussion of the specific interview themes participants were invited to remain and take part in a focus group, facilitated by CRs not involved in analysis of the interview transcripts, but who had a clear understanding of the crucial themes. No academic/non-consumer members of the team remained for the focus group, consistent with the overall project philosophy that consumers be interviewed by CRs.

Table 12: **Themes from mental health consumer interviews evaluating service provision.**

Identified theme	
1	Acceptance versus stigma
2	Informed and educated environment versus uninformed and uneducated environment
3	Power and powerlessness
4	Consumer involvement versus lack of consumer involvement
5	Optimal and appropriate versus inadequate and inappropriate medication experiences
6	High versus Low Service Quality System
7	Responsive/Unresponsive to consumers
8	Satisfying versus dissatisfying relationships with staff
9	Supportive versus unsupportive relationships with community, family and other consumers
10	All of me (I am more than my illness) versus “me” as an illness
11	diagnosis

Strong support for the analysis as presented was found in these feedback sessions. In addition participants made the following comments about the analysis: reference to the holistic nature of the themes as a positive feature of the analysis; the commonality of experience, no matter what diagnosis a consumer received; the themes described resonate with participants’ personal experience, and experience of other's known to participants. Some participants said that they agreed with the themes, based on their "lived experience".

At this point it is important to comment on the themes found in the focus groups and interviews. As Malins (in preparation) notes, the same negative stories of consumer's experience with mental health services are still being told and this is highly consistent with a number of other qualitative studies seeking to understand consumer's views and experiences of their health and illness as well as their experiences with services. In Victoria a review of consumer participation in mental health services identified that whilst a lot of effort is being put into consumer participation it appears their views and experiences are still not being adequately fed back into cycles of quality improvement in services (Service Quality Australia, 1999). Therefore it is reasonable to conclude that this problem has not been adequately resolved.

Quantitative Instrument Development[1]

The prime consideration in the development of the questionnaire was having a scale that was brief and easy to use. Initially it was envisaged a 22-item questionnaire would be developed, however this was revised to a 26-item questionnaire during the instrument development phase. To address issues of reliability and validity for the brief scale, the CEO-MHS 26 was developed in a number of stages. As a first step the second author of the project suggested 4 questions be developed for each of the 11 themes identified from the interview data. This lead to the development of a larger 44-item version of the scale and this was trailed with 209 consumers, 100 from mental health services and 109 from non-government services. Next, statistical analysis enabled the reduction of the 44-item version to a more manageable and still meaningful 26-item questionnaire. The process for the development of the CEO-MHS 26 is summarised in Table 13 and a more detailed account follows.

Table 13: Process to develop the CEO-MHS 26

Steps	Process
1	Team meet twice to brainstorm questions in relation to the 11 interview themes
2	Smaller team meet twice to revise and reduce the questions to 10 per interview theme in accordance to set principles
3	Revised questions circulated
4	Small team further revised and reduced questions to 6 per interview theme
5	Small team further reduce questions to 4 per interview item and develop protocol for CRs to administer the questionnaire
6	Small team meet to finalise questionnaire
7	Questionnaire piloted
8	Questionnaire administered to 209 consumers
9	Statistical Analysis to determine psychometric properties of questionnaire

In the first step, 12 CRs and three academic researchers met on two occasions to brainstorm questions in relation to the 11 interview themes. This process yielded an

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[1] Josephine Law, a student from the Clinical Psychology Masters program, was involved in the development of the Quantitative Instrument for her thesis project.

exhaustive and rich list of 156 questions. At this meeting the group decided on a 5 point Likert scale (1 meaning strongly disagree, 2 meaning disagree, 3 being neutral, 4 meaning agree and 5 meaning strongly agree) because it more easily approximates a continuous scale whilst at the same time providing information about direction and intensity of response.

Second, a smaller team consisting of a 1 CR and 2 university researchers met to revise, format and reduce the instrument questions to 10 for each theme. Six principles were established to guide this process and these were: the items should be in statement format; the items should be in first person wherever possible; the number of questions for each theme should be reduced to ten; the statements need to be rewritten if necessary to be consistent with a 5-point Likert scale; the items should include both positively and negatively worded items; and the items need to be related to evaluating services.

Third, the questions from stage 2 were circulated to the wider team for comment. The fourth step involved a team consisting of 1 CR and 3 Academic researchers undertaking further refinement and reduction of the 10 questions per theme to 6 per theme. In this step, wording was checked for clarity and the 6 items were chosen by group consensus.

In the fifth step, a CR and an Academic researcher reduced the items from 6 to 4 and developed a protocol for the CRs to administer the resulting 44-item questionnaire. The Masters student attached to this part of the project, in consultation with her supervisor, then balanced positively and negatively worded questions, ensured the items were in active voice, and randomised the items by using a random table. The balancing of positive and negatively worded questions was undertaken to neutralise response-set effects. For example a positively phrased question was “I feel respected by service staff”, and a negatively phrased question was “My first contact with this service was negative.” At the next meeting of this team the demographic information sheet, the project information sheet for participants and the consent form were developed.

The sixth step involved all CRs and Academic researchers endorsing (after minor wording changes) the 44-item questionnaire, the protocol for the CRs on the questionnaire administration, the demographic data sheet, the project information sheet and the consent form for participants.

In the seventh step the 44-item questionnaire was piloted with seven people who were in-patients at the local mental health unit. The consumers completing the questionnaire reported the questions were understandable and the CRs endorsed the administration procedure and documentation.

Following the successful piloting of the 44-item questionnaire, the eight step involved administering it to 100 consumers in the mental health service and 109 from the non-government service sector, a total of 209 consumers. Consumers in the mental health service were mainly inpatients of acute service at psychiatric hospitals whereas consumers of NGO were outpatients attending skills training workshops or residents of community residential service provided by NGO. The final step, the statistical analysis, was conducted on the resulting data to determine the psychometric properties of the development of the questionnaire to date. This phase is presented in the next section.

Psychometric properties of the instruments[2]

At the beginning of the project a much larger sample and more thorough psychometric testing was planned, however as the project progressed this was not feasible. Therefore, following suggestions from some experts (Norman & Streiner, 1994), the project team aimed to include at least five respondents per item (a total of 220 respondents) to allow adequate factor analysis of the data. A total of 221 consumers completed the questionnaire however only 209 of these were complete and therefore used in the final analysis. The demographic data for the respondents follows. Of the 209 respondents 106 were male, 102 female and one not identified. The respondents' age ranged from 16 to 83 with a mean age of 40.98 years, however there was a significant difference in mean age between the two groups. The mean age for respondents from the mental health service was 38.1 years and 43.86 years for the non-government service respondents (t= -3.191, p= 0.002). Respondent's educational level appears in Table 14, employment status at the time of participation in Table 15 and their annual income level in Table 16. As previously stated 100 respondents used mental health services and 109 used non-government services. There were no significant differences between respondents from the different services in terms of their educational level, employment status or annual income.

Table 14: <u>Respondents' educational level</u>

	Frequency	Percent	Cumulative Percent
< Year 10	45	22.8	22.8
Year 10 to 11	42	21.3	44.2
Year 12	32	16.2	60.4
TAFE or diploma	44	22.3	82.7
Apprenticeship or short course	4	2	84.8
University degree	30	15.2	100

Table 15: <u>Respondents' employment status</u>

	Frequency	Percent	Cumulative Percent
Full-time employment	14	7.7	7.7
Part-time employment	13	7.1	14.8
Casual employment	11	6	20.9
Pension/sickness		62.1	83
benefit	113	11.5	94.5
Unemployed	31	5.5	100
Retired	10		

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[2] The majority of the information contained in this section is from Law, J (in preparation) A Pilot Development of a Consumer Constructed Questionnaire to Evaluate Mental Health Service Provision in Australia Public Mental Health Services and non government organizations.

Table 16: **Respondent's annual income**

	Frequency	Percent	Cumulative Percent
$0 - $9,999	109	59.6	59.6
$10,000 - $19,999	53	29.0	88.5
$20,000 - $29,999	7	3.8	92.3
$30,000 - $39,999	7	3.8	96.2
above $40,000	7	3.8	100

The negatively worded items on the questionnaire were reverse scored before analysis to enable a consistency of higher scores reflecting higher satisfaction with services. To explore the factor structure of the 44 items, three factor extraction techniques (Principal Components, Principal Axis Factoring and Maximum Likelihood) with oblique rotation were conducted. A two-factor structure was found to be robust across different extraction techniques supporting the construct validity of the items. Items with a factor loading equal to 0.5 or above were retained. Eigenvalues also exceeded 1 for each factor and no items showed cross loadings on more than one factor. The total variance explained by the two factors ranged from 33.8% (Maximum Likelihood extraction) to 36.7% (Principal Component extraction). Therefore, the final scale consisted of 26 items. Table 17 displays the factor loadings of these 26 items.

Reliability tests indicate Factor 1 appears to be positively worded whereas items in Factor 2 are negatively worded. Factor 1 has therefore been labelled Positive Experience with Mental Health Services and Factor 2 labelled as Negative Experience with Mental Health Services. The reliability for the resulting 26-item questionnaire is very good with a Cronbach Alpha of 0.9174 (n=178). Internal consistency was then tested for this two-factor scale. The internal consistencies for the two factors were satisfactory, with Cronbach Alpha of 0.9224 for Factor 1 and 0.7973 for Factor 2. Corrected Item-Total correlation ranged from 0.5329 to 0.7316 for Factor 1 and from 0.3193 to 0.6234 for Factor 2. The data was further divided into Illawarra Health/ Government and NGO. Internal consistencies of the two factors for the two subgroups were satisfactory as well. Table 18 illustrates the Cronbach Alpha for the sample.

Table 17: **Factor loadings for the scale**

CEO items		Factor 1	Factor 2
Factor 1	13	.668	
	14	.605	
	15	.687	
	17	.579	
	20	.689	
	21	.534	
	22	.670	
	24	.626	
	29	.546	
	31	.641	
	35	.585	
	38	.528	

CEO items		**Factor 1**	**Factor 2**
	39	.641	
	41	.707	
	42	.625	
	43	.553	
	44	.670	
Factor 2	2		.516
	5		.506
	9		.564
	11		.532
	18		.642
	25		.608
	26		.590
	30		.613
	33		.577
Eigenvalue		13.718	2.435
% variance		31.177	5.535
Cumulative %		31.177	36.712

Table 18: Internal consistencies for CEO-MHS 26 scale

	Cronbach Alpha	
	Factor 1	**Factor 2**
Whole sample	0.9224 (n=188)	0.7973 (n=188)
Illawarra Health/ Government	0.8965 (n=98)	0.7859 (n=101)
NGO	0.9406 (n=90)	0.8126 (n=87)
No. of items	17	9

The final 26 items represented all themes identified from the interview data. The interview theme, included question and the related factor appear in Table 19.

Table 19: CEO-MHS 26 items, related interview theme and factor.

Interview theme	**Factor**	**Questionnaire item**
1. Stigma	1	This service helps consumers overcome any stigma they hold about themselves
1. Stigma	1	This service has helped me cope well with stigma
1. Stigma	2	I experience stigma from mental health professionals/persons associated with this service
2. Information and education	1	This service has provided me with excellent information on mental health
2. Information and education	1	This service keeps the community well informed on mental health issues
2. Information and education	2	The staff of this service have not been educated about what it is like to experience a mental illness

Interview theme	Factor	Questionnaire item
3. Power and powerlessness	1	This service has empowered me
3. Power and powerlessness	1	This service encourages me to have control over my treatment
4. Consumer involvement	1	I think the consumer participation in this service is excellent
4. Consumer involvement	1	This service provides many opportunities for consumer participation
5. Medication	1	This service helps me manage the side effects of my medication
5. Medication	2	I have not been given adequate information about my medication and side effects
6. System issues	1	I feel safe and secure when being looked after by this service
6. System issues	2	This service does not follow-up consumers after they are discharged from hospital
7. Responsive to consumers	1	Service staff consult me on most decisions made
7. Responsive to consumers	1	My right to choice of treatment was respected by the service
7. Responsive to consumers	2	Service staff are ignorant to my needs
7. Responsive to consumers	2	This service makes me feel like a number
8. Relationships with staff	1	Service staff understand me
8. Relationships with staff	2	I am not taken seriously by service staff
9. Relationships with community, family & consumers	1	This service encourages consumers to support each other
9. Relationships with community, family & consumers	2	This service does not give me the option to include my family or close friends in my recovery
10. All of me	1	This service assisted me to learn more about myself
10. All of me	1	This service assists me to cope with living with my mental illness
11. Diagnosis	1	This service is responsive when my symptoms change
11. Diagnosis	1	I would like to have received my diagnosis in this service earlier

No significant difference was found on gender, educational level, annual income and current employment status when the respondents were compared according to whether they received services from mental health or the non-government sector and their responses on the reduced 26 items questionnaire. However a significant difference was found between these two groups in terms of age for 3 of the 26-item questionnaire. This information appears in Table 20.

Table 20. Significant difference on age between Mental Health service and NGO's for items on 26-item questionnaire

Item	t-value	df	p=
Q2. The staff of this service have not been educated about what it is like to experience a mental illness.	2.121	205	0.035
Q15. This service assisted me to learn more about myself	-2.096	206	0.037
Q33. I am not taken seriously by service staff	-2.312	201	0.022

In summation the CEO-MHS 26 is still in a preliminary stage of development, however its' factor structure has been established and a satisfactory internal consistency demonstrated. There is initial indication that the structure of the scale provides some support for its content validity (see Table 19) and construct validity. However the amount of variance accounted for by the two factors, whilst reasonable in the first instance, indicates the scale needs further developmental work and this needs to be undertaken in further studies. Other studies will then be needed to establish its test-retest reliability and criterion validity by testing the questionnaire in different time frames and including other criterion variables that measures mental health consumer satisfaction.

Evaluation Framework development

At the inception of the project, the following questions were asked, “who is the evaluation for?” and “who judges the value of a service?” We asked these questions because, whilst the project was not an evaluation in and of itself, it was about evaluation. These types of questions are typically asked at the beginning of any service evaluation and the relevant stakeholders identified. However, as we have argued in Chapter 1, mental health service evaluation has particular difficulties because the key stakeholders, the consumers, have historically been disenfranchised. We have argued that whilst national and international mental health service policy and plans actively attempt to redress this by mandating consumer participation and partnership, this has not been particularly successful in the area of service evaluation.

The project team’s understanding of evaluation that underpins the development of the CEO-MHS Evaluation Framework is that evaluation includes: measurement, or systematic data collection; description; judgement; an attempt to create or implement change based on this judgement; and that evaluation in itself is a political activity.

It is important to reiterate here our earlier comments on the findings from the focus groups and the interviews in this project. As Malins (in preparation) notes, the same negative stores of consumer’s experience with mental health services are still being told and this is highly consistent with a number of other qualitative studies seeking to understand consumer’s views and experiences of their health and illness, as well as their experiences with services. In Victoria a review of consumer participation in mental health services identified that whilst a lot of effort is being put into consumer participation, it appears their views and experiences are still not being adequately fed back into cycles of quality improvement in services (Service Quality Australia, 1999). Therefore it is reasonable to conclude that this problem has not been adequately resolved because consumer views are still not being adequately integrated into service change processes. This supports our view that as well as adequate and appropriate survey instruments to elicit consumers’ views an explicit protocol is also needed that identifies how findings will be implemented to effect service change. The CEO-MHS Evaluation Framework provides both as well as having mental health consumers actively drive the development of every aspect of the evaluation framework in a transparent and well-documented process.

The actual evaluation framework is presented in Chapter 4. The framework provides the theoretical and philosophical basis of the evaluation, the CEO-MHS, and explains the reasons that motivated the choices made. The evaluation framework grew out of the qualitative data collection phase and, in part, is testable via the quantitative tool, the

CEO-MHS 26. Ultimately the value of any evaluation framework can only be determined by its usefulness and ability to identify if endeavours to meet the unmet needs of key stakeholders work (Wadsworth, 1997) as well as identifying areas where change is necessary and actually begins to effect this change.

The CEO-MHS Evaluation Framework was developed over a series of thirteen meetings between ten CRs, the two Consumer Representatives who sat on the Project's Management Committee, the Project Officer and the PhD student attached to the project. The Project Officer and the PhD student shared the preparation, organization and facilitation of the 13 meetings. In addition, other members of the management committee sometimes attended meetings and provided feedback at regular intervals throughout this developmental phase. The PhD student was responsible for guiding the initial literature review and guiding the in-depth discussions including the consideration of the Responsive Constructivist Evaluation (Guba & Lincoln, 1994) and Empowerment Evaluation (Fetterman, 1996). These latter types of evaluations were discussed because of their resonance with the overall values underpinning CEO-MHS. The topics discussed over the thirteen meetings to develop the CEO-MHS Evaluation Framework appear in Table 21. Other topics were implicit in our processes to date, and became articulated during these Evaluation Framework meetings.

Table 21: <u>Topics discussed in CEO-MHS Evaluation Framework Development Meetings</u>

1. Learning about evaluation methods and reviewing literature relating to evaluation
2. Reflection on the groups experiences of collaboration and conducting the CEO-MHS research in the two years prior to commencement of these meetings
3. Consideration of the themes that emerged from the focus groups and interviews
4. Using these themes to generate items for questionnaire development
5. Reflection on the values of the CEO-MHS project

SECTION 4:

CEO-MHS EVALUATION FRAMEWORK[3] AND OTHER PROJECT OUTPUTS

In the previous chapter the development of the CEO-MHS Evaluation Framework was outlined and readers are referred to section 3.3.3 for this information. In summary, the development of the evaluation framework has been ongoing since the commencement of the project. It has involved literature reviews, conducting focus groups and interviews with consumers, analysis of the data, development of the quantitative instrument the CEO-MHS 26, meetings to reflect on the process, and the documentation of the values, principles and steps of the CEO-MHS Evaluation Framework. This chapter provides a summary of the latter. It is important to note that while the framework is largely complete it still requires further development and the complete CEO-MHS Evaluation Framework is being prepared for publication as a manual.

The evaluation framework is presented, beginning with our values and principles and following these, the steps involved in conducting a CEO-MHS. This presentation is partly influenced by the manner in which Guba and Lincoln's (1994) Responsive Constructivist Evaluation was presented, however, was also adopted so the beliefs underpinning our framework are clearly stated.

Values of the CEO-MHS Evaluation Framework

The values underpinning a CEO-MHS evaluation appear in Table 22 and brief descriptions of each of the values follow.

Table 22: Values underpinning a Consumer Evaluation of Mental Health Service (CEO-MHS)

1. Consumers as experts: valuing lived experience
2. Consumer participation: giving consumers a voice
3. Improvement of
    a. The broader community
    b. Mental Health Services
    c. Consumer status within the broader community and mental health services
    d. Roles for consumers
4. Care, respect and empathy
5. Empowerment
6. Power through sharing knowledge and experiences
7. Collaboration

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[3] The information on the CEO-MHS Evaluation Framework presented here is the work of a number of team members who were involved in its development.

Value 1: Consumers as experts – value of lived experience

Consumers are the people who have direct experiences using Mental Health Services (MHS). For some, these experiences have been positive, others have endured arduous ordeals within the MHS. Whether positive or negative, we believe because of these experiences consumers have specific expertise that is vital to an evaluation of MHS, a perspective shared by others such as Lloyd and King (2003). We, therefore, consider consumers experts when evaluating the MHS, holding valuable information about services. It makes sense to turn to consumer's experiences to guide and advocate changes within the system that they use. We believe evaluation needs consumer's expertise and lived experiences to have a more effective, realistic, and fully meaningful impact on the system. Additionally, the issue of social justice is arguably enforced when the skills of the consumers are sought after and deemed as a valuable resource by the MHS. It is also important not to fall into the trap of tokenism where consumers are overworked or under-utilised (Stacey & Heron, 2002). Therefore, within a CEO-MHS evaluation, consumers are central to both conducting and informing the evaluation process.

Value 2: Consumer participation: Giving consumers a voice.

"Consumer participation is about power and the redistribution of power" (Church, 1996, p29 cited in Stacey & Herron, 2002 p7). Lammers & Happell (2003) identified a range of benefits both for consumers and services as a result of participation. While there is no 'one'consumer voice (Epstein & Olsen, 1998), we believe, as do others (Hutshinson & Ausland, 1992/3), that consumers' voices must be heard within services. For a long time, many consumers have felt their voice has not been heard, even ignored within the mental health system and the broader community (Lammers & Happell, 2003., Liberati, A., 1997).

A CEO-MHS evaluation seeks to create one mechanism within services where the obstacles and setbacks identified elsewhere within this report can be overturned, by giving consumers a voice with which to be heard and empowered through evaluation. In a CEO-MHS evaluation, consumers should have input into every stage of the evaluation process, as outlined in our principles and steps. For this to occur successfully, interactions based on care, respect and empathy should be actively sought.

Value 3: Working for improvement, of:

a. The broader community;
b. Mental Health Services;
c. Consumer Status within MHS and the broader community; and
d. Consumer Researcher (consumer rep, consumer consultant, consumer advocate) status

Our understanding of evaluation stresses the importance of evaluation findings being used: that is, evaluation is part of a continuing cycle of improvement. We see mental health services firstly as situated within the broader community. Consumers, staff, carers, etc. are all part of a broader context. Thus we believe a consumer evaluation of any service should therefore be working towards improvement of that community. In parallel, we believe that the mental health service should be working towards improvement of itself. We also explicitly see consumer evaluation as about working toward improvement of the status of consumers (a major focus), within both services and the broader community context and one mechanism to challenge the stigma of mental illness.

Value 4: Care, respect and empathy

"In order for collaboration to be a lived commitment it must occur with integrity. It requires faith, encouragement, and risk. People both give and gain from collaboration." (Byas et al., 2002, p83). Clearly care, respect and empathy form the basis of any relationship. Yet, as we have identified earlier, consumers repeatedly report violation of these basic values. However relationships with staff appear to be central to many consumers' experiences of the services, because of this, relationships will also play a central role in any evaluation effort. A consumer evaluation should be conducted in a manner that facilitates care, respect, and empathy between all involved. Staff, in particular, because of the at-times poor treatment of consumers by them, need to pay close attention to these values when involved in a consumer evaluation, to ensure genuine and continued stakeholder involvement.

Value 5: Empowerment

a. *Challenges and or acknowledges existing power structures at all levels*
b. *Creating environments for personal empowerment*

In addition to the embededness of individuals and communities within historical and cultural processes, individuals, organisations, and communities are grounded within contextual processes that maintain or destabilise positions of relative power and privilege (Tseng et al., 2002). We refer here to a definition of power in terms of the ability to act and to control resources. While the term power often refers to a state of being (either having or not having power), the term empowerment more readily lends itself to a process orientation. Additionally, Speer and Hughey (1995) conceptualise empowerment as occurring at the individual, organisational, and community levels of analysis. The consumer movement has a major interest in consumer empowerment (Kaufmann, 1999).

Value 6: Power through sharing knowledge and experiences

Value 6 is closely linked to the previous value about empowerment and also to the participatory and action research paradigm used in this project, where knowledge is assumed to be a source of power in society (Nelson, Ochocka, Griffin and Lord, 1998).

We have addressed the disempowerment and unequal power relationships between mental health service providers and consumers in greater detail elsewhere in the report. This value is about shifting power by sharing knowledge. As Byas et al (2002) note: "Collaborative research enables the development of 'shared constructions' of good service and outcomes through gaining access to untapped knowledge and experiences leading to an overall 'expansion of knowledge'. By stepping out of traditionally defined roles…both workers and consumers are opened to new learning and understanding that otherwise may not have been realised." (p. 84).

Value 7: Working together/ Collaboration

While our earlier values clearly place consumers' centrally in evaluation research in mental health services, this value highlights the importance of collaborative relationships in effective evaluation and change. We believe that both consumers and professionals have important perspectives to bring to evaluation, and while we strongly advocate that consumers' perspectives must be the focus of evaluation, professionals too need to be involved. However, this value raises the important need to develop new ways of relating so that such collaboration or working together can bring equality to the fore. The foundations, from our experience, of effective collaboration, lie in allowing different views to be raised, and heard.

4.2 Principles of the CEO-MHS Evaluation Framework

The principles underlying the CEO-MHS Evaluation Framework appear in Table 23 and are briefly described in the following section.

Table 23: <u>Principles to conduct a Consumer Evaluation of Mental Health Services</u>

1. Consumers should be involved and acknowledged in every step of the evaluation to empower consumers in a proactive role within the MHS
2. The evaluation process should seek to further legitimise the role of consumer researchers and evaluators
3. The evaluation process should aim to reduce stigma from the community and self-stigma towards mental health consumers
4. The evaluation process should aim to redress power imbalances experienced by consumers when dealing with the mental health service
5. The evaluation process should result in consumers being better informed about the system of service provision
6. During the evaluation process all stakeholders should be encouraged to work towards the improvement of quality of life of consumers
7. During the evaluation process all stakeholders should be encouraged to recognise the need for regular consumer evaluations of services
8. All stakeholders should be involved in the evaluation process, after consumers have decided the issues
9. Information should be analysed by consumer stakeholders for the process to be a valid consumer evaluation
10. The evaluation cycle should be completed by stakeholders implementing and evaluating some of the changes suggested as a result of the evaluation

1. *Consumers should be involved and acknowledged in every step of the evaluation to empower consumers in a proactive role within the MHS*

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A consumer-focussed evaluation is a new approach to evaluation of MHS and needs to ensure consumers' claims, concerns and issues are listened to in a frank and open manner as referred to in Values 1 and 2. Consumers obviously are the best persons to comment on the delivery of the service, as stated in Value 1. It is essential during this process that consumers are empowered to speak for themselves. Taking proactive roles and taking on tasks that will improve the quality of the service must involve consumers and this involvement must be acknowledged.

2. *The evaluation process should seek to further legitimise the role of consumer researchers and evaluators*

Essentially this project has been about legitimising the role of consumers as researchers and evaluators and there is no question that this has been successfully achieved. However this principle acknowledges legitimising consumers as researchers and evaluators is an ongoing process that can only be fully integrated into mainstream evaluation over time. As part of the CEO-MHS Project Consumer researchers have received training and developed this evaluation framework that gives them unique characteristics to help facilitate the Evaluation Process. As well as this, consumer representatives, consumer advocates, and consumer consultants have been working in the service for a long time and have built up relationships with consumers and staff. These relationships will be invaluable in ensuring a true and honest response from staff and consumers during the evaluation process.

3. *The evaluation process should aim to reduce stigma from the community and self-stigma towards mental health consumers*

Having consumers conduct the evaluation will create an opportunity for stakeholders to see consumers performing in competent and professional roles. Seeing consumers in this way will ensure community members, being stakeholders, will have a more positive view of consumers with mental illness. In addition, with improved self confidence and an important part to play in the mental health service, consumers will see themselves in a better light restoring confidence in themselves. Giving consumers a voice creates an opportunity whereby consumers' views can be more understood, thus helping reduce stigma. Creating environments for personal empowerment eliminates self-stigma, for those that have been affected by it.

4. *The evaluation process should aim to redress power imbalances experienced by consumers when dealing with the mental health service*

This principle is closely related to Value 5 about empowerment. Our conception of empowerment focuses on the process of communities gaining greater access to and control over resources, and resonates quite well with the conception offered in the organising principle of PCIO (Spear & Hughey, 1995). These principles state that (1) social power is accessed through organisations, which hold power to the extent that members collectively pursue a common goal, (2) social power is built on the strength of interpersonal relationships, rather than commitment to a particular issue, and (3) individual empowerment must be grounded in a dialectic of action and reflection. Therefore this principle suggests that the power imbalances should be addressed during the evaluation process. As Value 5 indicates through sharing knowledge and experience consumers are empowered and this alters the balance of power in the Mental Health System. Value 5 states that power should be shared through knowledge and experience and this is vital to improving the welfare of consumers.

5. *The evaluation process should result in consumers being better informed about the system of service provision*

Consumer status is improved by being better informed about the system. In any effective partnership where you are working collaboratively, the consumers involved also become informed about how the system works. One important implication of having more information about the system is greater ability to advocate, both for oneself and others.

6. *During the evaluation process all stakeholders should be encouraged to work towards the improvement of quality of life of consumers*

Working for improvement of consumer status is a key value of this evaluation framework and we believe that by conducting a consumer evaluation where consumers' views guide changes made to the service, a consequence will be improved subjective quality of life for consumers. For this to occur requires not only the need for equality amongst all stakeholders but also the privileging of the lived experience of mental illness.

7. *During the evaluation process all stakeholders should be encouraged to recognise the need for regular consumer evaluations of services*

There is a need for regular evaluation because of its influence on the change cycle because regular evaluation ensures ongoing improvement of the service. This is an underlying theme of Value 3, improving the Mental Health Service, and links to our definition of evaluation. While completing one consumer evaluation is of itself useful, regular cycles of consumer evaluation are more powerful in implementing consumer directed change within the service.

8. *All stakeholders should be involved in the evaluation process, after consumers have decided the issues*

An implication of our values is that all stakeholders need to be involved if genuine change is to occur. While the evaluation process will be focussed around consumer's concerns and issues, all stakeholders need to be valued and involved in the implementation of the evaluation process.

9. *Information should be analysed by consumer stakeholders for the process to be a valid consumer evaluation*

As Value 1 states, we hold that consumers are experts in their experiences, and that it is consumers' experiences and their expertise around which an evaluation of MHS should be based: the evaluation process should be a place where consumers' voices can be expressed and heard (Value 2). From these values then, it follows that any information collected throughout the evaluation from consumers should have consumers' involved in interpreting the meanings from it. As Values 5 and 6 indicate, however, analysis may be a joint venture, however consumers must be involved.

10. The evaluation cycle should be completed by stakeholders implementing and evaluating some of the changes suggested as a result of the evaluation

This principle is self-explanatory.

Steps to implement a CEO-MHS Evaluation of Mental Health Services

The values and principles underlying the CEO-MHS Evaluation have been identified above and the following steps indicate how it is suggested the evaluation proceed. The steps are summarised in Table 24 and a brief description of each step follows.

Table 24: Steps required to conduct a consumer evaluation of mental health services

1. Establish a need, authorisation and recruit personnel
2. Collect information about the organisation and previous evaluations conducted
3. Identify stakeholders
4. Administer the CEO-MHS 26 and facilitate focus groups
5. Form an evaluation committee and analyse information consistent with the CEO-MHS principles
6. Feedback analysis to consumer stakeholders
7. Consumer stakeholders validate the analysis and prioritise issues
8. Feedback and discuss findings with other stakeholders
9. Set goals and develop strategies and tasks with all stakeholders
10. Conduct a second round of data collection and analysis (optional)
11. Feedback to stakeholders (optional)
12. Write a report and give recommendations

Step1: Establishing need, authorisation and recruit personnel

The following identifies key aspects of this step: consumer representatives or advocates establish the need for a consumer led evaluation of the organisation or entity; Ideally this is developed into a proposal; quality relationships between various stakeholder groups is critical to the success of the evaluation; upon approval of the evaluation it is recommended that a contract or document outlining the following key areas be developed: (a) authorisation and consent to the evaluation by relevant parties (b) identification of the evaluators (c) identification of the entity to be evaluated; recruitment personnel; ideally form an Evaluation Team consisting of consumer representatives/advocates and/or consumers of the MHS and appoint a Co-ordinator for the project and it is highly desirable this position be filled by a consumer.

Step 2: Collect information about the organisation and previous evaluations conducted

During this initial phase of the evaluation it is recommended that the Evaluation Team identify what services are offered by the entity under evaluation and what services are actually being evaluated. A clear understanding by the Evaluation Team at this point will assist when members of the team are facilitating the evaluation with service users. It will also be of assistance to gain access to previous evaluations as this will provide some initial insight regarding the operation of the service. During this process it is suggested that a summary of the main findings of those previous evaluations considered most relevant be formulated. Some tips for information gathering include the following:

- gain access to organisational website
- refer to the organisational chart
- liaise with Quality Assurance Manager (or similar position) to access previous evaluations

Step 3: Identify stakeholders

Examples of stakeholder groups that may be identified include mental health service staff, carers, consumers and other organisations involved in the running of the MHS.

Step 4: Administration of the CEO-MHS 26 and facilitate focus groups

The CEO-MHS 26 will be administered to the consumers (who have agreed to participate in the evaluation) of the service by a team of consumer researchers/ advocates/representatives. The main aim of this step is to analyse the data to identify key areas for closer review later on in the evaluation process. The findings should form the basis of focus group questions. Participants of focus groups should consist of volunteers enlisted by the Evaluation team at existing group meetings. Other alternatives to garner participants could involve recruitment through the media or through mail advice.

Step 5: Form an evaluation committee and analyse information consistent with the CEO-MHS principles

The information from the Focus Groups needs to be analysed and categorised into main points and considered together with the findings from the administration of the CEO-MHS 26. The findings should be presented in the form of a draft preliminary report.

Step 6: Feedback of analysis to consumer stakeholders

This should occur during a meeting ‘face to face’ so that analysis can be explained fully by the evaluation team.

Step 7: Consumer stakeholders validate the analysis and prioritise issues

Consumer stakeholders are asked if the process by which the findings were established has been accurate, (e.g.,) did the focus group questions adequately reflect the findings from the questionnaire data? Also, consumer stakeholders are required to reach consensus on the prioritisation of issues raised using findings from the CEO-MHS 26 and Focus Groups and their existing knowledge of the MHS under evaluation.

Step 8: Feedback and discuss findings with other stakeholders

The evaluation team then report the preliminary results and accurately express the issues raised by consumers and the prioritisation of issues are explained to all stakeholders. CRs should clarify any issues that stakeholders do not understand.

Step 9: Set goals and develop strategies and tasks with all stakeholders

It is recommended that all stakeholders be involved in setting goals and developing the appropriate strategies and tasks required to achieve these goals. This is to acknowledge the importance of, and nurture the various between group partnerships that make the evaluation possible in the first instance and contribute to it's overall success. Various stakeholders may be crucial in executing the required changes resulting from the employment of specific goals, strategies and tasks.

Step 10: Conduct a second round of data collection and analysis (this step is preferable but optional)

This second round of data collection only takes place if time and resources allow. The aim is to provide more comprehensive information and also serves as a check on the reliability and validity of the first phase of data collection.

Step 11: Feedback to stakeholders (optional)

This step involves the distribution of analysed data from Step 10 to all the stakeholders. The analysed data could be presented in written form. It is the same as Step 6, only it concerns all stakeholders, not just consumers.

Step 12: Write report and give recommendations

The report will present a comprehensive account of the process and results of the evaluation and will provide recommendations for change.

Achievement of Objectives

The project was grounded in Participatory Action Research therefore it is not unusual to find that the project deviated in some ways from the original proposal. One of the major aims of this project was to demonstrate the credibility of consumers in conducting research. This has been more than adequately demonstrated within this project. In particular their ability to be active co-researchers was demonstrated to all members of the project team. If the project had achieved nothing else, this outcome made it a worthwhile endeavour and one essential to breaking the stereotyping of consumers as passive recipients of services with little to offer in contrast to being active participants.

Strength and significance of the project

The strength and significance of this project is that it is the first large scale project in Australia where mental health consumers actively drove every aspect of the project.

Hence the results and outcomes truly reflect consumer driven and directed initiatives and redresses the current power imbalance between professionals, expert researchers and mental health consumers. This project "has heard the consumer voice". The research has demonstrated mental health consumers are extremely valuable members of the mental health research team and capable of competently undertaking the many aspects of the role of researcher. To date they have been an untapped resource because of the implicit assumption in the mental health field that people who have the lived experience of mental illness are not and cannot be credible due to the very nature of their disorder. This research has refuted this position and demonstrated consumers are credible and their involvement significantly increases the validity of mental health research. Mental Health Services are ultimately there to meet their needs and who better to judge if the service actually works in this respect. There is now a local team of trained consumer researchers who are capable of working with the Mental Health staff.

Positive gains for consumers

There have been a number of positive gains for consumers who participated in this project. The Consumer Researchers have acted as role models to other consumers. They have gained a number of invaluable skills and are now well prepared to take the roles of active collaborator and participator in mental health services. Australian State and Commonwealth governments now mandate mental health consumers are to be active participants and collaborators in all aspects of the mental health service system. To ensure this occurs mental health services are measured against the National Standards for Mental Health Services (Commonwealth of Australia, 1997). Standard 3 relates directly to Consumer Participation. The findings and the tools developed from this project will enable the operationalisation of consumer feedback to improve mental health services.

Specific outputs from the project

Specific outputs from the project follow:

- Detailed information on the training needs of mental health consumers to undertake research and evaluation
- A number of findings from the project have been widely disseminated. Details can be found in Appendix 5.
- A comprehensive consumer driven and directed Evaluation Framework for use in mental health services
- A short 26-item questionnaire to be used as a part of the evaluation framework.

The latter is an important progressive step that goes beyond the standard customer satisfaction surveys that have been shown to be limited largely due to their irrelevance to things that matter to consumers. Satisfaction surveys are typically developed by professionals and administered by them.

Contributions made by the project

The contributions the project has made are also included and these are described below.

Local Contribution

1. The University of Wollongong offered Honorary Fellowships to the AI's of the project, significantly enhancing their credibility as researchers and acknowledging their contribution to the project.

2. The University of Wollongong employed fourteen consumers who were paid as research assistants. As a part of the project these consumer researchers were trained in: interviewing skills; conducting focus groups; academic writing and presentation skills including the use of Power Point; critical thinking skills to assist in the thematic analysis of interview data; and questionnaire development.

3. The Consumer Researchers as a result of their involvement in this project have been employed in a number of other projects within the University of Wollongong and Illawarra Health.

State Contribution

1. The members of the project team are currently in collaboration with other groups such as the NSW Consumer Advisory Group regarding separated consumer-orientated projects and conferences.

National Contribution

1. The methodology and preliminary findings have been presented widely.

2. The consumer researchers have received feedback from other consumers that they have inspired hope in them. This has occurred as a result of the consumer researchers presenting the project and their involvement in it at Local, State and National Conferences.

3. The project has attracted interest from state and territory directors of mental health services and at the request of Dr Harvey Whiteford, became a standing item on the National Mental Health Training Advisory Group Agenda (2001-2002).

Further developments as a result of the project

The following developments have occurred as a direct result of the project:

1. Members of the CEO-MHS project were approached to submit a proposal to conduct a consumer evaluation of the implementation of the new Mental Health Strategic Plan and at the time of writing the application appears to have been successful.

2. The APAI PhD student is now employed full-time by the NSW CAG and directly involved in their consumer initiatives.

3. Cathy Bentley has enrolled in a PhD in Psychology to pursue carer initiatives that developed as an extension of this project.

Collaboration with the industry partner, the IAHS

There was close collaboration with the Illawarra Area Health Service (IAHS) throughout the project and this was facilitated by the strategic alliance that existed between the University of Wollongong (UOW), the Faculty of Health and Behavioural Science and the IAHS prior to the commencement of the project. In fact the project grew out of this strategic alliance. The two Consumer Initiatives Coordinators employed by the IAHS were the AIs on the project. One of the PIs (Gordon Lambert) held a joint appointment between the UOW and the IAHS. This also applied to Lindsay Oades the other PI on the project, however Dr Oades resigned from the IAHS to take up a lectureship with the UOW midway through the project. The Quality Management Coordinator for the IAHS was a member of the Project Management Committee and facilitated various aspects of the project. The Director of Mental Health Services fully supported the project ensuring the required collaboration to complete the project. In essence, the UOW required access to consumers of mental health services and the IAHS required training of consumers to take up collaborative roles now mandated by Commonwealth and State governments. Therefore the involvement was beneficial for all parties involved in this project.

Greater appreciation of IAHS needs as result of project

The National Standards for Mental Health Services (Commonwealth of Australia, 1997) mandates involving consumers in all aspects of project development, planning and management. Therefore any information on consumer involvement greatly fosters understanding and appreciation of the needs of consumers, particularly in relation to training needs. This project has been unique in that it has essentially enabled "research to be conducted within research". Specifically, one Masters student in Clinical Psychology researched the training needs of consumers to become researchers for her thesis, and the APAI PhD student researchered the consumer’s experience of being researchers. Therefore this project provided numerous insights and greatly fostered an understanding and appreciation of training needs of consumers to be involved in the participation and collaboration now required between consumers and mental health services.

Challenges experienced with the project

Some challenges were encountered but this was expected when asking people to take roles unfamiliar to them but also because we were asking people to take roles previously denied to them. Indeed this was a new experience for most of the people involved in the project. Some of the specific challenges for the timely completion project follow:

- CRs not being able to participate on a consistent basis due to other work commitments and in some cases the development of psychiatric symptoms. Though this was anticipated and accounted for in the structure/framework of the original proposal (i.e., appointment of a pool of 14 consumer researchers) it has resulted in protracted completion times for tasks such as conducting interviews, data analysis, questionnaire development and administration, and development of the evaluation framework.

- The decision by the Consumer Researchers to work in pairs for support has compounded the above in relation to timelines. Whilst it would have been easy for the academic researchers to take over the process and meet deadlines, this would have invalidated the intent and purpose of the project.

- Dr Lindsay Oades resigned from the Illawarra Area Health Service to take up a position at the University of Wollongong. Mr Gordon Lambert retired at the end of 2003 and the Project Officer resigned at the end of December 2003 to have a child.

Awards conferred on project.

The project has been the recipient of the following awards:

1. Gold award for Service Excellence Australian and New Zealand THEMHS Conference Gold Coast Queensland 2004.

2. Mental Health Matters certificate awarded 2003 by the NSW Department of Health and presented by the NSW Governor

3. Malins, G.L. Oades, L.G., & Viney, L.L. (2002). Consuming constructs: Why are mental health consumers asked to passively consume services? Paper presented at the 6th European PCP Conference, Florence, Italy. Awarded the First European Personal Construct Psychology Doctoral Student Prize.

SECTION 5:

CONSUMERS EXPERIENCES OF BECOMING RESEARCHERS[4]

Exploring the experiences of the consumers on the CEO-MHS team in becoming researchers was the subject of Gillian Malins' PhD thesis. This component of the research emerged as an important aspect for the team to understand and document as the CEO-MHS project progressed. The following provides a background to this part of the project.

While there is a growing call within international literature and policy for greater involvement of consumers as researchers in mental health research, to date few studies have been conducted exploring consumers' experiences as researchers (Henry, Nicholson, Clayfield, Phillips, & Steir, 2002). Three studies exist that provide some background to the area: Reeve et al., (2002) discuss the experiences of three consumer researchers (CRs) employed on a project titled: 'Shifting the paradigm in community mental health: A community study of Implementation and Change" conducted in Canada; Morrell-Bellai & Boydell (1994) examined the experiences of six mental health consumers involved as paid researchers, working on various projects under differing conditions ranging from being employed to complete specific research tasks, to involvement in the entire research process, also conducted in Canada; and Henry et al., (2002) describe employment of consumers as research assistants (RAs) in a university-based mental health research centre at the University of Massachusetts in America.

Reeve et al., (2002) discuss a broad range of issues related to their experiences, from their expectations entering the project to how they contributed personally to the research findings and processes. Twelve threads common to the accounts of these CRs are: the importance of time for building trust and testing relationships; the challenge of facing 'self as consumer'; gaining skills; that they built confidence in their own ability; that a team approach is useful; being involved gave them an experience of being heard and respected, valued; creation of environment that allowed "me to be me"; empathy when they struggled; the challenge of maintaining "objectivity" during interviews; role reversals – when interviewing professionals; technical challenges; being involved helped with personal recovery; and developing new meanings and beliefs.

Morrell-Bellai & Boydell were interested in what the benefits of being involved in research were, if any, for the participants, as well as identifying what special needs may arise for consumers being employed as researchers. They conducted semi-structured interviews with the consumers to address these questions. Their analysis leaves the question of what the experience of becoming a researcher is like unanswered, although their discussion indicates some areas that may be important: relationships within the research team and a sense of being supported; confidence and the link training plays in this. Their analysis indicates that benefits for the consumers interviewed related to a sense of greater self-esteem, and they reported feeling their experiences in research had been educative.

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[4] This section was written by the Gillian Malins and is based on her PhD research conducted as part of the project.

The focus of Henry et al's (2002) report is a description of how the RA positions developed, employee characteristics, job characteristics and responsibilities, the orientation and training provided, as well as supports and workplace accommodations that were necessary in their experience, and "boundary" issues encountered. A small component of the report is dedicated to describing the rewards and challenges of the research roles, from the perspective of the consumers who filled them. The positions described by Henry et al., (2002) were 12 part-time RA positions. Eight of these were developed using a transitional employment approach; the other four used a supported employment approach. Henry et al., (2002) describe one of the critical differences between these approaches as permanency of the position. The transitional employment places are time-limited, while supported employment positions are filled on a more permanent basis. According to Henry et al., (2002), 22 consumers have filled these positions since the inception of the first four RA positions in 1997. In outlining the rewards and challenges of the job, Henry et al., (2002) report on data collected with RAs at the time of job termination, in the form of self-administered exit questionnaires. These authors report that positive aspects of the job identified by RAs included: the opportunity to use or gain skills; the sense of mastery and confidence gained through the work; the variety in the work; reciprocal relationships RAs developed with peers and supervisors; a sense of empowerment felt at work; and a sense of self-respect derived from work in the research setting. The negative aspects of the job highlighted in this report include: the lack of predictability in work and changing nature of tasks. These aspects of the job were linked to feelings of stress for RAs.

Two other sources provide some insight into the experiences of consumers as researchers. In the report by Rose (2001) describing User Focused Monitoring conducted in the UK, a chapter is dedicated to accounts of the experience of UFM written by consumers from the UFM teams. Fifteen accounts are provided, and while many provide a sequential account of UFM itself, most provide some information about the personal experience of the researcher as well. The UFM researchers spoke of feeling uncertainty and apprehension, particularly when first becoming involved in UFM, and on conducting their first interviews. They spoke of finding the interview situations both inspirational and sad; as well, challenging and tiring. One mentioned how the interviews at times brought up painful memories from their own past. Overall, the results of being involved in UFM appeared to be reported as positive. The researchers spoke about greater confidence and growing courage, feeling satisfied and rewarded when they completed the UFM. One researcher said they felt they had done things they previously thought they never would. One researcher spoke about being shown, by her involvement that she is "a capable person" as opposed to the "useless waste of space" she felt before (Rose, 2001, p. 26). Another researcher spoke of a sense of disappointment, however, that the UFM experience had not lead to permanent work.

The second alternative source of information about the experiences of consumers as researchers comes from the "Researchers Self-Reflections" in the final report of the Understanding and Involvement Project (U&I) (Wadsworth & Epstein, 1996), a project conducted in Australia. Epstein worked several days a week as a researcher throughout the U&I project, and reflected: "the project has …been an essential nourishing factor in my own metamorphosis back into worthwhile life" (p. 193). Epstein writes of the role her work as a researcher on the U&I project played in "doing something", but also the multiple challenges she faced personally and professionally over the course of the three years. Epstein also describes the immense validation she found for her own meanings, finding confirmation for the sense she had made of her past experiences talking to other consumers through the project. Other consumers who worked as researchers on the U&I project reflected on their confusion, and the questioning of self that occurred in the very early stages of becoming involved. This same researcher indicates the emotional journey being a researcher can entail: “I feel one moment totally in despair and another moment fully involved and a worthwhile contributor” (p. 197). Another wrote about experiencing relief as he came to a realisation of community, understanding that he is not alone in his suffering.

In addition to these reports, literature exploring mental health consumers’ experiences of work more generally is relevant, as one of the fundamental aspects of the consumer researchers experiences with the CEO-MHS project is its work role. While there is a larger body of literature available discussing work for consumers of mental health services, Schneider (1998) notes, however, that in general, the non-economic outcomes linked to work for consumers have yet to be fully explored.

Strong (1997) has used an ethnographic approach to examine what makes work meaningful for people with persistent mental illness, also exploring how this meaningfulness relates to recovery. Strong found that the experience of work held complex, varying meanings for consumers. Four overlapping and interacting themes that framed the meaning of work were: living with a label; becoming a capable person with a future; getting on with life; and finding a place in this world. Strong notes that an important implication of her study is that consumers: “emphasised issues related to recovery and disabling environments rather than community reintegration or hospital recidivism” (p. 37). Kirsh has also conducted studies to examine the meaning of work and important elements of workplaces as perceived by mental health consumers (2000) and to explore factors that facilitate workplace reintegration as perceived by consumers (1996). Similar to Strong’s findings, Kirsh reports themes relating to the meaningfulness of work in terms of contributing to society, being challenged and achieving (Kirsh, 2000), and that emphasise holistic approaches (Kirsh, 1996) and the importance of the work environment (2000; 1996). Further exploration of the links between work and recovery has been reported by Provencher, Gregg, Mead & Mueser (2002) who have argued, based on findings from semi-structured interviews with 14 working and non-working consumers, that work is perceived by consumers as a means of self-empowerment, as well, perceived as promoting a sense of self-actualisation. These authors argue that work is closely linked to the experience of recovery.

A specific area of work that possibly holds much in common with that of becoming a researcher in the mental health field is consumers’ experiences of becoming mental health professionals. Paulson (1991) highlights issues related to reliving the past, and whether or not consumers want their experiences recognised in their new roles. Mowbray, Moxley and Collins (1998) describe the personal benefits identified by consumers who worked as peer support specialists in mental health settings as including: income; the reward of having a job; gaining skills that are transferable to other employment situations; becoming reinvolved in the routine of work; learning about themselves and how to handle a variety of difficult situations; the challenges offered that are not available in “sheltered” work settings; personal growth; and friendship. The costs, or negative features of their work are described by Mowbray et al., as including: dealing with difficulties, for example clients who were not cooperative, and the frustration and anger the peer support specialists felt often at these times; costs to their well-being, for example experiencing job stress, uncertainty about how to do the job, lack of support from supervisors and administrators, and a feeling of worry relating to the responsibility the position entailed; and finally the challenges of determining and maintaining boundaries.

There is clearly a gap in the literature about mental health consumer involvement in evaluative research. While much has been written about the importance of having consumers involved, description and explanation of what this process means to consumers is limited. While greater acceptance of the need for genuine consumer involvement and collaboration in research is becoming more broadly accepted, it is important to understand more about what it is like for consumers. Currently no model is available that describes what is experienced by consumers becoming researchers, providing consumers and other researchers with a framework for making consumer research successful. The literature reviewed here indicates, however, that filling research roles, like other work roles, may play a part in assisting consumers define a hopeful, active self who can anticipate a positive future.

Method

Ten consumers from the team agreed to take part in this component of the research: nine were employed as CRs and one was a consumer consultant from the management committee. Participants were already employed in their roles with the CEO-MHS project when they were invited to participate in this study. Initially, they were informed about this research study at a general team meeting, and were given written information and consent forms to take away. The voluntary nature of consent in both the verbal and written information provided to CRs was stressed at this point, particularly because of the relationship that had developed over the prior two years between the participants and PhD student.

In order to develop a clear understanding of what the experience of becoming a researcher had been like for these participants, they took part in a focus group and two interviews. During the focus group, participants were asked to particularly consider if and how the themes from the CEO-MHS interviews resonated with their experiences working on the CEO-MHS project. Participants were posted a copy of the focus group questions several days prior to the group being held, so they had time to consider the issues that would be raised before the discussion if they chose. Gillian Malins facilitated this focus group.

Participants also took part in two semi-structured interviews with the PhD student. Before the first interview, the participants completed a “snake” or “winding river” chart (adapted from Denicolo, 1996; Tjok-a-Tam & Denicolo, 1996; Pope & Denicolo, 1991). Participants in this study were asked to reflect on their lives since becoming involved in the CEO-MHS project, visualising and drawing this period as a snake or river, with each turn or bend representing a critical incident or point for them within this period. During the interview, joint reflection on the ‘snake’ charts then occurred. Additionally, the Experience Cycle Methodology (ECM), as described by Oades and Viney (2000) was adapted, encouraging participants to tell their story of being involved in the CEO-MHS project, using the experience cycle as a guide for the interviewer in eliciting CRs’ stories. Before the second interview, participants were asked to complete two self-characterisations (Kelly, 1955/1991) sequentially: the first asked them to write about themselves as they were when they first became involved in the CEO-MHS project, and the second used the standard instructions, asking them to write about themselves at the present time. The second semi-structured interview was conducted once participants had completed both self-characterisations. This interview commenced with a discussion based around a set of questions derived from Epting, Probert and Pittman's "Let's Just Say" method (1993). Then, joint reflection on participants' self-characterisations occurred.

Analysis of the data

Qualitative analysis of the data was conducted, using Interpretative Phenomenological Analysis (IPA) in an attempt to understand the experience of becoming researchers for the consumers involved in the project. This method was consistent with the analyses of the CEO-MHS focus group and interview data described earlier. CRs were involved in reviewing the initial analysis performed by Gillian, and then were provided with opportunities to review the results as they were drafted for publication.

Experience of becoming a mental health evaluation researcher

Analysis of the focus group and interview data resulted in the following findings:

- Verification that the themes that arose from CEO-MHS interviews were integral to the experiences of becoming researchers for the CRs involved
- Seven further themes emerged specific to the experience of becoming researchers. These themes were labelled:

  1. Having a job versus not
  2. The positives and negatives of the work environment
  3. Broadening personal horizons versus a narrowing world
     - Self: personal growth
     - The importance of relationships versus isolation
     - Learning
     - New experiences, new perspectives
     - The unknown
  4. Positive and negative emotional experiences of being a researcher
  5. Doing the job versus the rest of life: The context of becoming a researcher
  6. Playing an active role versus not being engaged
  7. Growing empowerment versus power imbalance.

The experience of becoming a researcher was different for each participant; however, the themes indicate the common experience also. For some of the consumers involved, this was their first paid job after a significant period of time. Only a few had been more actively involved in the paid work force recently. The features of being in work played an integral role in the experience of becoming a researcher for all CRs. For them, to be paid for the work they did, to have the opportunity to feel they were contributing to society, and to have a place to go were all-important aspects of the experience. The themes that emerged reveal the experience of becoming a researcher to be multifaceted and complex, accompanied by a dearth of positive and negative emotions, and personal opportunities and challenges. The interlinking of a deeply personal journey with inherently social processes is highlighted in the themes resulting from interviews with consumers. Becoming and being a researcher was tremendously challenging but concurrently deeply rewarding and satisfying for these consumers, and linked intimately to their experiences and identification as mental health consumers. The experience of becoming a researcher, as described by the participants in this study, appears to include many elements that feature in descriptions of journeys of recovery (Davidson & Stauss, 1992; Deegan, 1998; Ridgway, 2001).

Discussion regarding self-esteem and confidence, and the theme of *Growing empowerment versus power imbalances* indicate that participants saw themselves as more capable, valued, and confident, with a greater sense of place in the world, through their roles as researchers and the opportunities these provided. Participants clearly found the process of being involved as researchers one that challenged their perceptions of themselves, and several participants described clear reconstruction.

The results of this study contribute centrally to two bodies of current literature: firstly the literature regarding consumers' active involvement in mental health research and evaluation; and secondly, work literature. The results of this study highlight that not only does consumer involvement hold enormous benefit and essential checks to the research process itself (Goodare & Lockwood, 1999; Liberati, 1997), but also, that the process of becoming a researcher can be one mechanism consumers' could use to assist their recovery. These results have implications for mental health service policy and provision, as well as for research in the mental health field.

SECTION 6:

DISCUSSION

The overall aim of the project was to utilise the as yet untapped resource of consumers as mental health researchers to develop a consumer driven and directed method of evaluating mental health services to lead to service improvement. We argued that to date consumers have not been considered credible and therefore they have been a largely untapped resource within the mental health system. The difference between this project and other projects, and what makes it unique, is that the consumers were not only employed and trained as researchers and collaborators, they actively drove the development of the Evaluation Framework, one of the major outputs of the project. Such an approach requires privileging the knowledge that comes from the lived experience of mental illness and hence valuing this ‘expert’ knowledge in a similar vain to ‘expert’ professional and academic knowledge.

The values and beliefs underlying the project and outlined in the introduction, enabled the genuine participation and partnership that was required amongst project team members. This has taken consumer involvement in research to the next step of involvement in mental health system evaluation. That is, the project has provided a genuine consumer voice about the evaluation of mental health services.

To ensure the successful participation of consumers in the research process, in the early stages of the project the entire group of 14-consumer researcher’s undertook a training program. The three-day training program was designed according to the identified learning needs of the consumers and included: practical research skills; communication and interpersonal skills; development of objectivity; establishing boundaries; having an informal training atmosphere; having frequent breaks; and receiving feedback, positive reinforcement and support. This information was derived from interviews, focus groups and the “Let’s Just Say” technique with the consumer researchers at the commencement of the project. Whilst the CRs prior knowledge of research was somewhat stereotypical at the beginning of the project, the training did increase their knowledge of research skills, particularly in relation to conducting interviews and focus groups. However nearly half of the CRs found the latter the most difficult aspect of the training because of the need to focus on more than one thing at a time, remember all the information and then provide a summary at the end. This could have occurred for a variety of reasons and warrants further attention at the individual level for all CRs in order to address what would work best for them in overcoming this problem. This approach is preferable to succumbing to the temptation of making ad hoc suggestions in isolation of identified individual need. In general, the training program increased the CRs self-confidence, and feelings of value because they were able to make a worthwhile contribution. For some it was important to have the additional skills to include on their CV to improve their future employment prospects.

The project has been able to identify very comprehensive information on the CRs experience of being researchers because it was the topic of the PhD student attached to the project. She found that while the experience was different for everyone, indeed it was multifaceted and complex; there were some common themes. Being in paid employment played an integral role for all the CRs. For them, to be paid for the work they did, to have the opportunity to feel they were contributing to society, and to have a place to go were all-important aspects of the experience. Becoming and being a researcher was tremendously challenging but also deeply rewarding and satisfying for these consumers. The results of this component of the project highlight that not only does consumer involvement hold enormous benefit and essential checks to the research process itself, but also that the process of becoming a researcher can be one mechanism consumers' could use to assist their recovery.

The research design and methodology of this project differed from other evaluations in mental health in three major ways. First, the research began with a comprehensive qualitative data collection phase that allowed for the development of the quantitative instrument, the CEO-MHS 26. Second, to increase the robustness of the qualitative data collection, focus groups were used in the formative phases of the research. Third, and most importantly, mental health consumers were used exclusively at all times for data collection and they actively drove the development of the CEO-MHS Evaluation Framework. The focus group and interview data were analysed using the IPA method of analysis because of its focus on meaning. The focus groups provided the information on which to form the questions for the interviews. Strong support for the analysis of the interview data was obtained from the interview participants who were asked 'did we get it right'? The interview data was then used to develop the quantitative instrument, the CEO-MHS 26. The process described here makes the CEO-MHS 26 very progressive and quite different to standard consumer satisfaction surveys that have been shown to be irrelevant to the things that matter to consumers.

The CEO-MHS 26, the quantitative instrument that forms part of the evaluation framework and resulted out of the qualitative data analysis, is still in a preliminary stage of development. However its factor structure has been established and a satisfactory internal consistency demonstrated. There is initial indication that the structure of the scale provides some support for its content validity and construct validity. However the amount of variance accounted for by the two factors, whilst reasonable in the first instance, indicates the scale needs further developmental work. This will need to be undertaken in future research to establish its test-retest reliability and criterion validity by testing the questionnaire in different time frames and including other criterion variables that measure mental health consumer satisfaction.

It is important to reiterate here that the same negative stories of consumers' experience with mental health services that have been found in a number of other qualitative studies were found in the focus groups and the interviews. This finding again leads to the conclusion that while a lot of effort has been put into consumer participation it appears their views and experiences are still not being adequately fed back into cycles of quality improvement in services as was found in Service Quality Australia (1999). Therefore it is reasonable to conclude that this problem has not been resolved because consumer views are still not being adequately integrated into service change processes. This supports our view that as well as adequate and appropriate survey instruments to elicit consumer's views, such as the CEO-MHS 26, an explicit protocol is also needed that identifies how these findings will be implemented to effect service change. The CEO-MHS Evaluation Framework provides both.

As we have previously stated, the CEO-MHS Evaluation Framework is being developed for publication as a manual. It was developed over a number of meetings and includes the values, principles and steps of the evaluation process. The value base of the evaluation process is one of its key strengths because, as we have argued, there is a need to redress a number of inequities for consumers within the mental health system. Clearly stated values in any endeavour are one way of redressing these issues. Ultimately, as Wadsworth (1997) notes, the value of any evaluation framework can only be determined by its usefulness and ability to identify if endeavours to meet the unmet needs of key stakeholders work.

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APPENDIX 1:

TRAINING MANUAL FOR CONSUMERS COMMENCING RESEARCH

CEO-MHS
CONSUMER EVALUATION OF MENTAL HEALTH SERVICES

A TRAINING MANUAL FOR CONSUMERS COMMENCING RESEARCH

Gillian Malins, Kim Morland & Lindsay Oades

CEO-MHS
CONSUMER EVALUATION OF MENTAL HEALTH SERVICES

A TRAINING MANUAL FOR CONSUMERS COMMENCING RESEARCH

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CONTENTS

INTRODUCTION TO THE TRAINING MANUAL

This training manual has been developed to support the Consumer Researchers working on CEO-MHS in developing and refining the skills and knowledge to conduct focus groups and interviews.

This training manual is a resource specifically for parts A and B of Stage 1 of the project (see Research Design section of manual for description of stages of the project).

This manual was developed to support a training day held in June 2002. An earlier version of the manual, developed in 2001 has been used in preparing this manual.

AIM AND LEARNING OUTCOMES

Aim:

To develop skills and knowledge in principles of research, with a specific focus on conducting focus groups and interviews within research contexts.

Learning Outcomes:

This manual will support consumers in developing:

- an understanding of principles of research at a general level
- specific understanding of the project CEO-MHS
- skills in facilitating focus groups
- skills in conducting interviews

INTRODUCTION TO RESEARCH

What is research?

Research is a way of collecting and understanding information and finding answers to questions you have set. It involves:

- A critical examination of something (the research area/topic);
- Posing questions and searching systematically for answers;
- Working within a framework or set of philosophies; and
- Using procedures, methods and techniques systematically in an attempt to answer the research question/s.

There are many different ways of conducting research, but there are some general characteristics that define research. These include:

- ***Being Rigorous***

  Researchers must make sure that the procedures they follow to address the research questions are relevant, appropriate and justified.

- ***Being systematic***

  The procedures undertaken generally follow a certain sequence, and some procedure must follow others. This is really about having a clear research design – considering each step in the research processes and how each one fits with the others.

- ***Being critical***

  Researchers have a role to be critical of the procedures used and the methods employed – both as the research is being conducted, and in reporting on the research study. Being critical is important in developing a useful research design, and in helping other people use the research appropriately. Other researchers will be able to utilise the things that worked well in the research, and consider how to do some things more effectively.

- ***Being valid, reliable and verifiable***

  Research can be evaluated by these criteria. Researchers need to make every attempt to meet these requirements.

  Validity – or credibility and transferability – relates to whether the findings of the research represent the beliefs/feelings and values of the participants rather than the researcher.

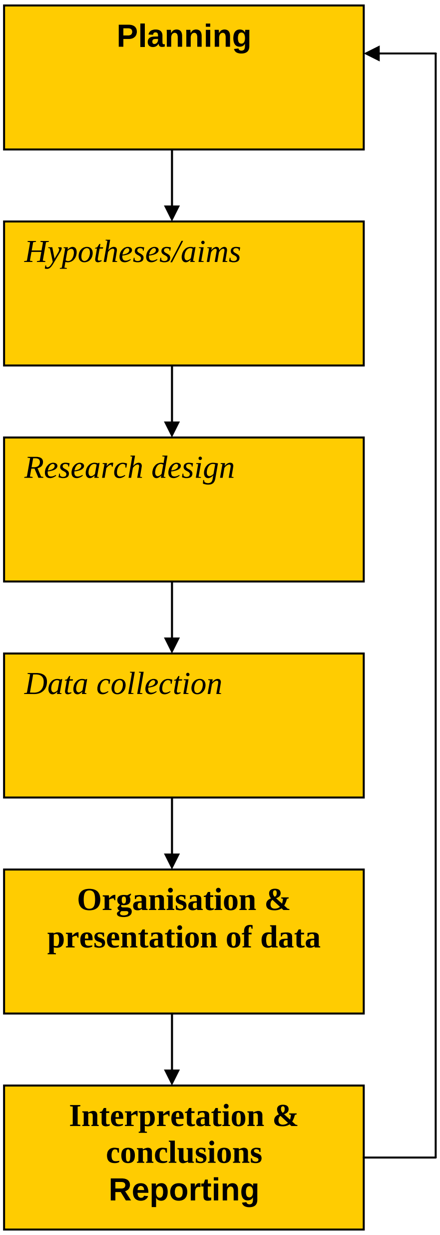
  This is about making sure your research is an unbiased attempt to answer the questions you are asking.

This characteristic of research also relates to how representative the findings are, and what settings the findings are applicable to.

Reliability – or dependability – relates to how closely the interpretations made by the researcher reflect what is being studied. A researcher needs to be able to show what they did, and how they reached the conclusions they reached.
Findings and conclusions of research also need to be checked and tested – this can be done in many ways. It may be checking your interpretation with the participants or with other researchers. One question to ask is *Can my work be replicated?*

The Research Process

While every research study is different, there is a general process that research follows. This is outlined below:



Some points about the Research Process.

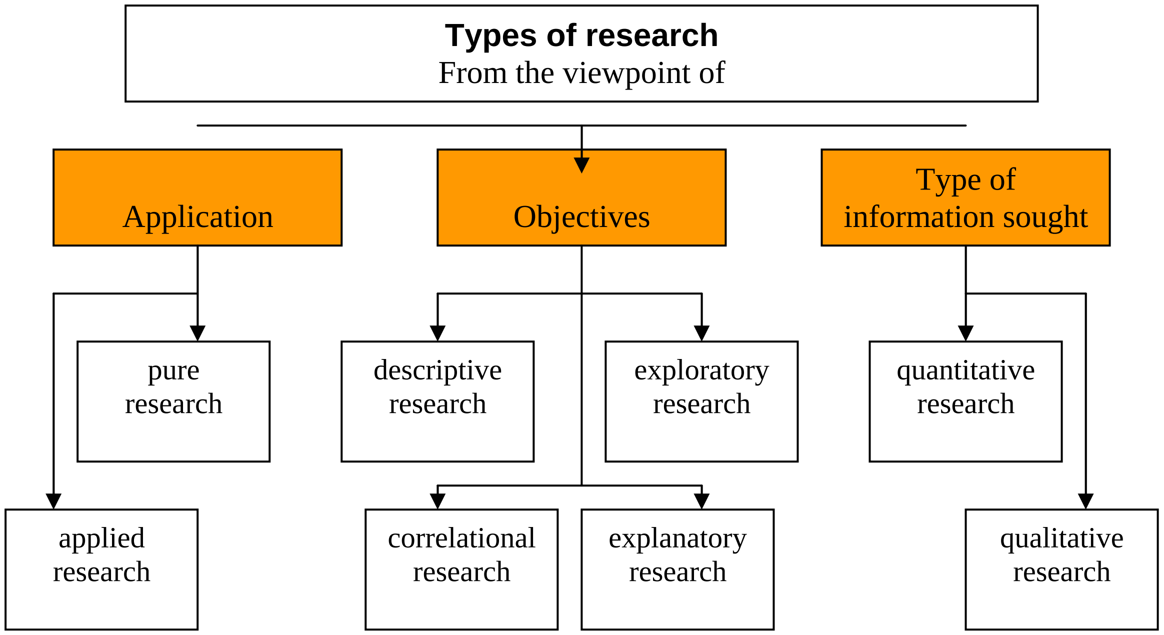
- Each part of the research process informs the next.
- While generally the aim is to move from planning through each step to the finished research, often research can involve moving up as well as down the steps. **These steps don't always work in such a linear way – but it is a good guide to what you are aiming to do in research.**

Types of research

Research can be classified according to

1. the application of the research
2. the objectives of the research
3. the type of information sought.

Kumar (1998) provides a useful diagram that explains these three perspectives.



- Any research study can be classified according to its application, objectives and the type of information sought.
- Most research does not fit into only one of these categories, but several.

Pure Research:

Involves developing and testing theories that may have no known practical application at the present time, or in the future. This research is conducted with an aim to add to the existing body of knowledge, rather than with an aim to apply what is learnt to practical situations.

Applied Research:

Involves research where an aim is to gain information that can be used in practical settings – for example for policy formation or administration.

Descriptive Research:

Attempts to describe something systematically. The focus of the research determines what is being described.

Correlational Research:

Attempts to discover or establish the existence of a relationship between two or more aspects of a situation**.**

Explanatory Research:

Also focuses on relationships between two or more aspects of a situation, however attempts to clarify why there is a relationship, and how the two things relate.

Exploratory Research:

Is interested in investigating an area, simply to discover some more about it. Research may be exploratory because there is not much known about the particular area. An exploratory research study might lead to a fuller investigation involving some of the other types of research above.

Quantitative Research:

Is when your aim is to quantify a problem or issue. For example, if you want to find out how often something occurs, you would be conducting quantitative research. This research involves using numerical data, and numbers are used in describing the results of the study.

Qualitative Research:

Is when non-numerical data is collected, and techniques that don't involve quantifying the data are used to make sense of it, and the research problem. Often qualitative research involves the use of textual data (eg: transcripts of things that people have said). The data gathered in qualitative research is often concerned with people's meanings or ways of viewing the particular topic being researched.

References & Further Reading: Introduction to research

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OVERVIEW OF THE PROJECT: CEO-MHS

Framework of this research

As discussed in the section *What is research?* researching involves working within a framework or from a particular philosophical position. The framework within which CEO-MHS is working includes the following:

- a belief that the researchers and those being researched need to work collaboratively, as they are co-researchers or participants, in the search for meaning.

- a belief that consumers of mental health services have expert knowledge about mental health services, their own requirements from services and service provision, and their own needs more generally.

- a belief that this expertise should contribute and be used in research and help guide the way the research is conducted.

- a belief that consumers of mental health services have the right to be involved in the development of any tool that is to be used in evaluating mental health services.

- a belief that any situation may be interpreted differently by different people, and that this needs to be considered and incorporated into research.

What type of research is this? How can CEO-MHS be classified?

If we use the categories described in the section above *Types of research* CEO-MHS can be classified according to its application, objectives, and the type of information used.

- To classify by application – CEO-MHS would be classed as **applied** research. Our findings will be able to be applied to mental health settings, which means the research has a practical use.

- To classify by objectives – CEO-MHS could be classed as both **exploratory** and **descriptive**.

- To classify by the type of information used – CEO-MHS could be classed as primarily **qualitative**. We are seeking people's views and opinions through taping and transcribing interviews – this means we are seeking qualitative data. The way we are analysing the information is also qualitative – that is we are not reducing this information to numbers. However, some of the latter parts of the project will involve turning the information we have into something where we can use numbers – so the research will also be **quantitative.**

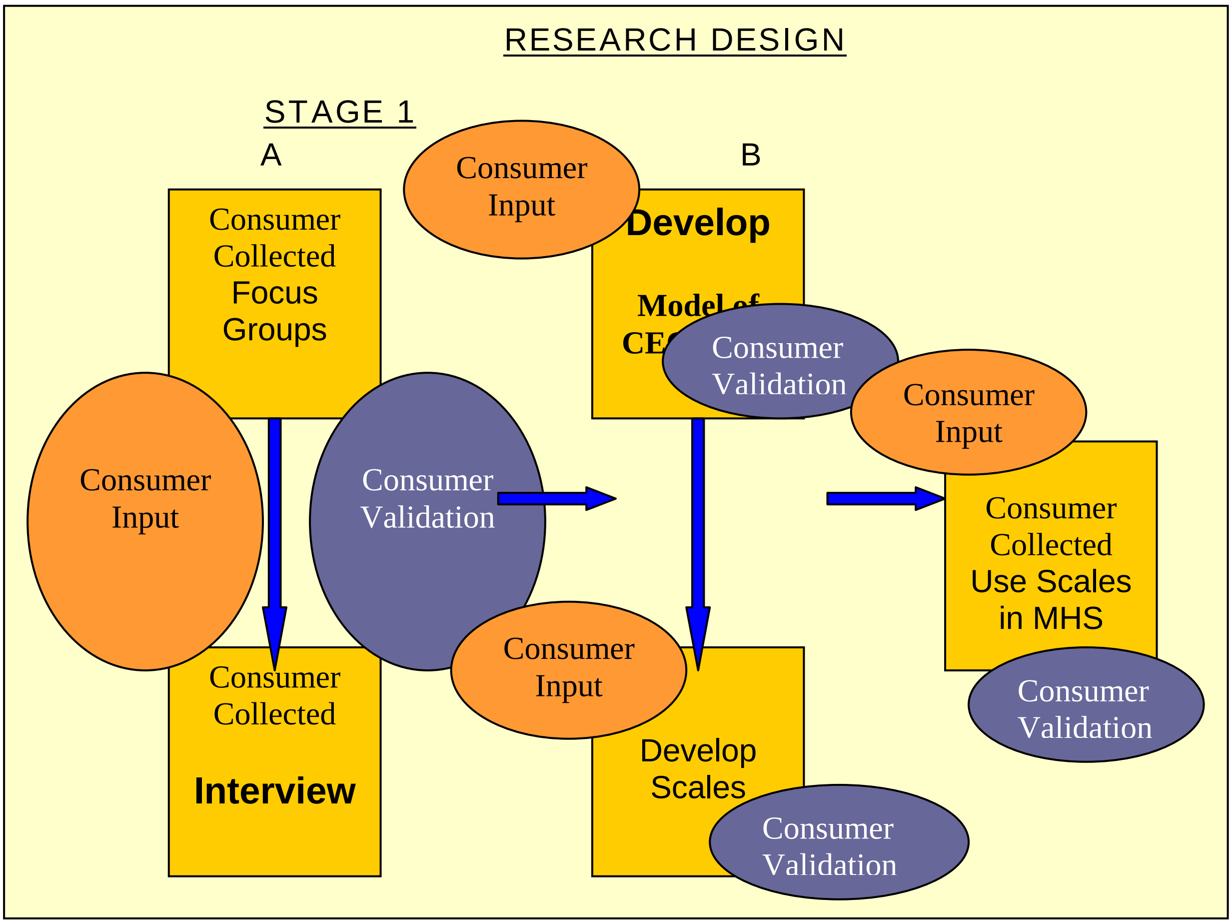
Aims of CEO-MHS

CEO-MHS is a 3-year research project with the following aims:

- to develop genuine collaboration between established researchers (University-based) and new researchers (consumers);
- to empower consumers through “credible” research;
- to develop consumer constructed instruments to evaluate MHS;
- to develop a model of CEO-MHS;
- to trial these instruments and this model in IAHS as a demonstration site for other AHS; and
- to employ and train researchers who are also consumers – to build capacity for future evaluations.

Research Design

To achieve the aims outlined above, the research is being conducted in two stages, which are shown in the diagram below:



Stage 1 of the Project

As outlined above, Stage 1 can be broken into two parts. Part A and Part B.
It is during Part A of Stage 1 that data collection occurs.

Specifically, the project will make use of focus groups, and interviews to find out from consumers who use public mental health services:

- what is important in a service; and
- what questions should be addressed in an evaluation of a service.

A Focus Group Facilitators Guide, and Interviewers Guide have been developed by the project team, and are separate documents to this manual.

FOCUS GROUPS

What is a Focus Group?

‘Focus Group’ is a term used in research to refer to a group discussion, where people with specific knowledge and expertise are invited to meet and talk about a topic to address a particular concern or research question.

Focus Groups are used in research to collect information that is important to the area being researched. They are a way to gain insight into the knowledge, thoughts and opinions of people.

Focus Groups involve:

- a group of people, usually between 6 & 10 but this can vary;
- a facilitator who guides the discussion in some way, often by introducing topics or asking questions, and encouraging everyone to talk;
- recording what happens as the group meets – this can be through tape recording, or note making, for example.

Focus groups can be very useful:

- Because they involve a group, it can feel more natural for the people participating;
- The group setting can help encourage discussion, and prompt people to talk about things;
- Focus Groups can be flexible, so that the facilitator can explore issues that arise in the discussion while the group is together;
- Focus groups allow a lot of data to be collected at once, because you are gaining the thoughts and opinions of more than one person in any meeting.

Focus Groups can also be challenging:

- Because they involve a group it can be difficult if people talk at once, or if one person dominates the group’s time – this can become a challenge for the facilitator and the whole group;
- Some people may find meeting and talking with a group difficult;
- Focus Groups can be difficult to organise because so many people are involved.

Why is CEO-MHS using Focus Groups?

We are using focus groups to get information from consumers of mental health services to develop more effective, consumer-centred interview questions.

By using focus groups, we aim to:

- ensure the research is guided by consumer input, and consumers' views;
- inform the way we interview, and what questions we ask; and
- make sure our interviews will be relevant to the consumers who take part, and ultimately the evaluation tools we develop will be relevant and useful to consumers.

The Focus Groups will:

- involve small groups of consumers talking about their experiences of mental health services, good and bad;
- be facilitated by Consumer Researchers employed as part of the CEO-MHS team;
- be analysed for recurring themes. These themes will help inform our interviewing.

The Facilitator's Role

The facilitator is responsible for keeping the flow of discussion going to ensure all the areas we want information about are covered in the discussion.

To do this the facilitator will have a guide, which will outline questions that can be posed to the group.

The facilitator works to create an atmosphere where people are willing to exchange feelings, thoughts and opinions about mental health services.

Your job as a facilitator will be:
- to encourage people to talk;
- to make sure that the material in the focus group guide is all covered;
- to help people feel safe and comfortable in the group;
- to draw out information from people in the group.

To do these things, you will have to:
1. listen; and
2. guide the discussion – without sharing your own views, experiences or stories.

It is important that the focus of the group discussion remains on the participant's views.

Facilitating Skills

These things are helpful in facilitating a group discussion:

- ask questions – follow-up interesting parts of the discussion with a question encouraging participants to explain further;

- show interest in group members;

- listen actively – let people know you are hearing them by nodding, making small comments like ‘uh-huh’, or smiling;

- try to make group members feel as comfortable as possible – with you, with the group, and in the room where the discussion is being held;

- use the facilitator guide to help you;

- <u>before the group begins, check that:</u>
  1. your equipment (the tape recorder, microphone) works; and
  2. that you know how to use it;

- be prepared - get to know what you have to do, practice, and become familiar with your facilitator’s guide.

Some things to avoid when facilitating:

- not paying attention;

- sharing your own view/opinions – this is not your role as a facilitator;

- using comments like “that’s correct” or “excellent” which may seem to be making a judgment, or indicate that there is a ‘right’ response. People in the group may be influenced by this;

- Being unprepared – feeling uncomfortable with your role, not knowing what to do;

- Being unfamiliar with the objectives and goals of the research.

Tips for facilitating:

- Maintain good eye contact with members of the group;

- Avoid letting one person dominate the discussion;

- Allow some silence following a question – don’t feel you have to fill up all the gaps. People will need some time to think about the questions;

- Keep in touch with your co-facilitator with eye contact. Remember you are working as a tem to keep the flow of discussion going.

Potential problems you may encounter in facilitating a focus group

Outlined below are some problems that can be commonly faced by a facilitator of a focus group. Below each are some suggestions for how to work with these situations.

1. **People who dominate the discussion.**

   You could use statements such as:
   "Thank you John. Are there others who want to comment on this question?"
   or
   "Does anyone feel differently?"
   or
   "Ben, it sounds like you've had a lot of experience in this. Does anyone else have another point of view?"

   Sometimes it can also help if someone is dominating to move your focus (i.e. stop looking at them) from them to another person in the group – especially if you can see that someone else wants to speak.

2. **Disruptive People**

   This might be someone who is constantly disagreeing, or arguing with other's in the group. They might not agree with other people's views. If this happens you might say something like:

   "We don't ask that you agree with others, but that you allow them to share their views."

3. **Shy, quiet people who may not respond to questions**

   Approach quiet members of the group gently, and in a friendly way. If they feel that the group's attention is directed towards them in a confrontational way, they may feel less willing to participate. You might say something like:

   "Sharon, you haven't had a chance to tell us what you think about this. How do you feel about .....?"

   "Brian, is there anything you'd like to add to what's been discussed?"

   It can also help to keep maintaining eye contact with quieter members of the group, and encouraging them by including them this way.

4. **Inattentive people**

   To gain their attention, refer to people by name. You could use one of the statements above, or something similar in this situation too, to bring someone whose thoughts have wandered back to the group.

If there’s an appropriate chance, you could also check if people need a few minutes break – or remind people they are welcome to grab a coffee/tea if you have these facilities available.

References & Further Reading: Focus Groups

Phan, T.T. & Fitzgerald, M.H. (1996). Guide for the use of focus groups in health research. *Culture and Mental Health, 1(1)*

INTERVIEWING

What is an interview?

> “ an interview is an encounter between a researcher and a respondent in which the latter is asked a series of questions relevant to the subject of the research. The respondent’s answers constitute the raw data analysed at a later point in time by the researcher.” (Ackroyd and Hughes, 1983: 66: cited in May, 1994)

Generally speaking there are three different types of interviews used in research. They are:

- Structured interviews
- Semi-structured interviews
- Unstructured interviews

Semi-structured interviews have been selected as one means of data collection for this project. An outline of this type of interview will be presented.

Semi-structured interviews

Aspects of semi-structured interviews:

- Most questions are specified or developed prior to the interview
- Interviewer is free to probe beyond the responses given by the interviewee
- Information regarding age, sex occupation etc is usually asked in a standardised format.
- Interviewer can seek both clarification and elaboration on the answers given.
- Allow the interviewee to answer more on their own terms than some other types of interviews.
- Provides some structure for comparability
- Interviewer is more of a facilitator or guide rather than dictating what will happen in the interview.

Attributes of a good interviewer

- Sensitivity
- Ability to establish a good rapport with a wide range of people ***
- To be motivating
- Friendly

- Positive
- Trustworthy
- A good listener and not to interrupt respondents before they have finished speaking
- To be committed and persevering
- To adopt a neutral manner or being non-judgemental (i.e. showing neither approval or disapproval)***
- To have a clear voice and ask one question at a time.

***These attributes will be dealt with in more detail.

These attributes can all be learned and practiced, we will in this instance be focussing on rapport building and being non-judgemental.

Interview techniques

Rapport

What is rapport?

- Rapport refers to:

> “ a basic sense of trust which has developed that allows for the free flow of information” . (Spradley 1979: 78 cited in May, 1994)

- Rapport provides the foundation of good interviewing.

Some points on rapport

- The degree to which the interviewer is able to establish a satisfactory rapport with the interviewee will affect the *reliability* of the information gathered at the interview. For instance if the interviewee feels uneasy or nervous then he or she may not feel like sharing their experiences or feelings with the interviewer.
- It is therefore necessary that interviewers are *positive* and *encouraging* towards interviewees, but at the same time that they *do not express their own views on the topic of the interview.*
- Interviewers need to be *tactful* when trying to make sure interviewees don’t ramble on or get off the topic of the interview.

How to establish rapport

- Introduce yourself, making it clear to the interviewee who you are. It is important that the participant feels comfortable with you.

- It is important to appear genuinely interested and accepting of the interviewee. One way to do this is to verbally encourage interviewees and let them know you are listening e.g. “uh huh, that’s interesting tell me more.”

- A little discussion of things like the weather, gardening, sporting scores etc can help put a participant at ease.

- Be clear about what is expected of the participant in the interview. The interviewee is much more likely to react openly if they understand and accept what they are there for.

- Make it very clear that the interview is confidential – reassure participants about this.

- Listen carefully to the participant, and let them know you are listening.

Being Non-Judgemental

- It is important that an interviewer does not appear to be judgemental.

- To make sure this does not occur, you need to create an atmosphere where the interviewee feels completely free to express any feeling or viewpoint. This atmosphere can be created by:

    - Making sure you remain objective - don’t state your own ideas, reactions or preferences to any question. Remember it is the participant’s view we need to hear.
    - Keep the focus on the participant.
    - Be accepting of their feelings and ideas – the things they tell you as they answer the questions you ask.

Probing

What is probing?

- Probing is a follow-up questioning technique used by the interviewer to stimulate discussion and obtain more information.
- It is a procedure which encourages and clarifies the thinking of the interviewee.

Why do I need to use probing?

- Some interviewees may give unclear or incomplete answers.
- Some interviewees may have difficulty putting their thoughts into words.
- Some interviewees may want to hide their responses because they feel embarrassed about them

Deciding when to use a probe

- Ask yourself if the interviewee has adequately answered the question – if you think they haven't, or you aren't sure, ask them if they can tell you anything more.
- Don't *assume* the interviewee has nothing more to say. Sometimes by probing you may receive more information.

Probing Tips

- *Probing should be neutral*.
    - This means probing needs to be done without introducing bias.
    - You shouldn't lead the interviewee or suggest or imply that some responses are more acceptable than others.
    - You need to understand the aim of the questions before probing can be used effectively.
- *Use open-ended questions to probe*.
    - Remember an open-ended question is one that encourages the participant to talk. They cannot give you a 'yes' or 'no' answer.
    - Usually an open-ended question starts with 'what' or 'how' or 'why'. Other good ways to make sure a question is open-ended is to ask someone to 'tell me more about...'

  - Closed ended questions give a participant more direction in how they can answer.

  - Using open-ended questions helps you ensure you are not leading the participant, that the interview remains unbiased and neutral. They help the focus remain on what the participant has to say.

Examples of probes

- Repeating the question.
- An expectant pause, accompanied, by a nod of the head
- A verbal ‘mm’ or ‘yes’ followed by an expectant pause
- A quizzical glance followed by an expectant pause.
- Repeating the reply, or paraphrasing it can stimulate the respondent to further thought Neutral comments or questions, such as “What do you mean by….?’ “Could you tell me more about your thinking on that?”. “Why do you feel that way?”

- If they have not given much information, you could try asking:

  - “Is there anything else you could add to that?”
  - “Can you tell me more about that?”
  - “That’s interesting, could you explain a little more?”

- If you are unclear what their answer means you can say:

  - “Could you explain that further, I’m a little unclear what you mean?”
  - “How do you mean?”
  - “Could you elaborate further?”

What to do if an interviewee says “I don’t know.”

- There are lots of possible reasons for this, eg. Vague opinions, fear to speak ones mind and lack of comprehension.

- Some ways to encourage the interviewee to respond are as follows:

  - “There are no right and wrong answers, we are just getting peoples ideas on this.

  - “Will you tell me what you have in mind?” or

  - Try asking the questions in a different way.

  - Trying some of the probes or encouragers above may also help.

The use of silence

Instead of firing a constant barrage of questions at the interviewee, the use of silence can be useful in interviewing. By allowing pauses in the conversation it may give interviewees the opportunity to think more deeply about an issue and then break the silence themselves with their new found information. Silence may feel awkward for you, but sometimes it is useful for the interviewee.

Working through the stages of the interview

The commencement of the interview

1. Establish rapport

- Introduce yourself. Tell them what you are doing and that you are employed by the University of Wollongong.
- Be polite, friendly but also professional.
- Casual chit-chat about the weather, sports scores etc., will help relax the interviewee.

2. Describe the purpose of the interview

- Tell them how their input will be helpful.
- Tell them that everything they tell you is confidential and anonymous.
- Tell them what the interview entails. Specifically, tell them how many questions they will be asked and the time it will take.
- Ask them if it is OK to tape record the interview.

3. Obtain the interviewees informed consent

- You cannot proceed with the interview without the persons consent. The form will clarify what the interview entails and how the information from it will be used in the project.

The interview itself

General tips:

1. Use the questions on the interview guide but you don’t have ask the questions exactly as they are written.
2. Read each question slowly and clearly
3. Look at the interviewee after asking a question in order to check if they have understood or are feeling uncomfortable. This should be dealt with immediately.

Your job in this section is to:

- let the interviewee tell you as much as they can about their attitude or opinion;

- probe to get more information as required. Try to help the interviewee
  a. open up and express their ideas
  b. express their ideas clearly
  c. explain and elaborate on their ideas.

The conclusion of the interview

1. Once the interviewee has nothing more to say in relation to the interview the **tape recorder must be turned off.**

2. Interviewers should thank the interviewee for taking part, letting them know that their contribution was valued and ask them if they had any questions they would like to ask about the study.

3. It is an important aim for interviewers to leave interviewees in a positive frame of mind at the conclusion of the interview. The interviewer should be prepared to spend some time listening to any concerns of the interviewee if this is appropriate. This is only polite after the interviewees have given up their own time for the study.

What to do if the interviewee wants to terminate the interview before it is finished?

- Interviewees/participants have the right to withdraw from the interview at any time. This right must be respected.

- If a participant decides they do not want to continue, you should:

  - turn the tape recorder off if you are already recording;

  - Ask the participant if they would like to talk about why they have decided not to continue (some people may tell you this without being asked);

  - Encourage the participant to contact another member of the research team to discuss anything they may need to – contact details are provided on the information sheets given to participants;

  - Encourage participants to talk to other people in their lives (family, friends, counsellors - whoever) if they don’t want to continue participating because they feel upset or disturbed;

  - Seek help at the time if you feel you or the participant needs it – contact another member of the project team.

References & Further Reading: Interviewing

Bowling, A. (1997) *Research methods in health: Investigating health and health services*. Open University Press, Buckingham, UK.

Kvale, S. (1996). *Interviews: An introduction to qualitative research interviewing.* Sage, Thousand Oaks, California.

May, T. (1994) *Social Research: Issues, methods and process*. Open University Press, Buckingham, UK.

Smith, J., Harre, R., & Van Langenhove, L. (1995). *Rethinking methods in psychology*. Sage, London

ETHICS AND CONFIDENTIALITY

What are ethics?

> “The word ethics often suggests a set of standards by which a particular group or community decides to regulate its behaviour – to distinguish what is legitimate or acceptable in pursuit of their aims from what is not.”.
> Flew 1984: 112: cited in May, 1994)

Researchers work to a set of ethical standards, and specifically CEO-MHS must work to the ethical guidelines set by the University of Wollongong Ethics Committee and the Illawarra Area Health Service Ethics Committee.

- The main ethical principal in regard to research is that respondents or in this case interviewees should not be harmed as a result of participating in the research.

- Participants/interviewees should give their informed consent to participate.

- The consent should be in writing and requested after each person has been given written information about the aims of the research, confidentiality and what risks, discomfort, benefits, procedures and questionnaires are involved.

- Interviewees/participants should also be advised that they are free to withdraw at any time.

Confidentiality

Confidentiality is a specific issue to consider within the ethical guidelines for research. In our application for approval from the ethics committees mentioned above, we discussed confidentiality in these terms:

“Researchers should not reveal names or information about any participant to anyone outside the research team.

All researchers working with participants will be asked to sign an agreement to work within this confidentiality agreement once they have participated in the training.

Numbers will be used to identify transcripts rather than names.

Names of participants will not be published in documentation of the research.”

- As a member of the research team, it is important for you to understand the ethical issues, particularly the issue of confidentiality.

References & Further Reading: Ethics and Confidentiality

May, T. (1994) *Social Research: Issues, methods and process*. Open University Press, **Buckingham, UK.**

SUPERVISION AND SUPPORT

While supervision and support overlap in some regards, the team views these as distinct processes. It is expected that:

- The team will continue to discuss supervision and support, what we mean by the terms, and how we provide both as a team;
- Consumer researcher members of the team will contribute to an understanding of their needs in terms of supervision and support;
- Different needs will be identified over time.

Supervision

Supervision within the context of this project will involve support in the research aspects of the positions.

Supervision includes the various training activities held as well as opportunities for external training that arise as part of the project. A specific supervision plan is needed for implementation while data collection is occurring.

When the Consumer Researchers (CR) begin interviewing, the following supervision plan is suggested:

1. Each CR will be contacted by phone or in person by Gillian Malins after first interview occurs.

2. Meetings on a regular basis with Gillian Malins (PhD student) while data collection is occurring. Supervision meetings will be held based on the following:

   a. *Frequency of interviewing*.

      Paid supervision meetings will be arranged contingent on frequency of interviewing. As a general rule, a paid supervision meeting (of up to 1 hour) will be arranged for every 5 interviews a CR conducts. On average, it is expected that CRs will conduct 10 interviews, so this will mean two individual supervision meetings each.

   b. *Support meetings with partner CR*

      CRs will be required to contact (by personal, mutual arrangement) a partner CR **before** arranging paid supervision meetings. It is expected that partner CRs will provide support for each other, and an opportunity to discuss any difficulties, concerns etc. helping to clarify issues that CRs want to bring to Individual Supervision meetings.

   c. *Difficulties arising*

      Paid supervision meetings will also be available on a needs basis, in addition to, or earlier than the general supervision meetings. CRs need to contact their partner CR as a first step, discussing their concerns and once they have done this, contact Gillian Malins to discuss arranging further/extra supervision.

It is proposed that individual meetings between the CR and Gillian Malins take the following form.

Consumer Researchers will be asked:

- How do you feel the interview/interviewing has gone?
- What do you feel you have done well in the interviewing?
- What difficulties have you faced in interviews?
- What would you like to do differently next time, if you have the chance?
- What further training do you feel you need?
- Do you have anything you want to ask or clarify with me?

Any other issues CRs want to raise can be discussed.

CRs will also be provided with feedback, based on the interviews transcribed that they have performed. This will be provided in one of 2 ways:

- with positive feedback given after they have responded to Q1 & 2 above, and constructive feedback given after they have responded to both Q3 & 4; or
- after they have responded to all of the first 4 questions.

3. Meeting of all CRs after 1 month of interviewing has occurred. This style of meeting will then occur on a regular 2 monthly basis until data collection is complete.

   These meetings will provide an opportunity for reciprocal feedback. Gillian will be able to provide general feedback about the CRs performance, and address any common training and educational needs to CRs as a group. CRs will be able to provide feedback as a group to Gillian.

It is proposed that the format of these meetings be as follows:

- General introduction, welcome.
- Provide some general feedback about progress of interviews, and conduct of interviews
- Address any common training/education needs
- CRs to discuss interview experiences in small groups (3 – 5 people/group). Any non-consumer members of the team may leave the room for this period.
- Consumer Representatives from the project management team may be asked to facilitate a general discussion if needed.
- In small groups they will be encouraged to discuss the following topics:

  1. what interviewing has been like for them;
  2. what they’ve liked, what they’ve disliked;
  3. what they have felt they’ve done well;
  4. what they feel has been difficult (have a few in the group had the same difficulties? How would others in the group deal with these problems/situations?);
  5. what they’d like to improve, in terms of their own skill/performance;
  6. what they would like to have further training in;
  7. any other issues that need to be raised/discussed

Support

The team views support as working together to meet the strains and stresses that are placed on the researchers in conducting the research, or integrating the research work into their lives beyond the research position. These strains and stresses may come from a variety of areas relating to the work as researchers, and include areas relevant to any research work: eg: managing timing and planning of interviews; working with equipment; handling difficult interviews etc. It is also anticipated that there may be some stresses specific to the researchers' identification as consumers: eg: needing to withdraw from work for a period; close identification with interviewees stories.

The purpose of support in the context of this project is to acknowledge that these strains and stresses may be part of the work of the researchers. While team members will have support to access through friends and family, it is also the responsibility of the research team to support each member when/if these are faced.

- It is anticipated that support is an area the whole team will be involved in.

- The researchers are key partners in the project team, and as such, play an active and vital role in supporting other team members.

- It is proposed that the team set up a series of options and pathways for support. This allows members to access a particular avenue, or several avenues of support, as desired. The supportive structures to be developed are outlined below.

  - ➢ Regular team meetings will be held:

    - of the whole project team, to provide an opportunity for the larger team to become aware of the work of the researchers, and their requirements for support from the team;

    - of the consumer researcher team, to allow an opportunity for these team members to discuss their experiences from the consumer perspective, and share their experiences in conducting the research with other researchers involved in data collection. These meetings could take two forms:
      1) Regular meetings could be conducted by those researchers from the Shoalhaven area and Wollongong area separately, or
      2) Meetings of all consumer researchers could be conducted, at a frequency which meets the needs of the researchers, but is also practical.

  - ➢ Contact details will be distributed so that all Consumer Researchers are able to contact other members of the project team, specifically the Project Officer and PhD student.

    Each researcher will be asked if they wish to include their contact phone number on a list to be distributed to all researchers. Researchers will be able to contact each other when/if they require support.

Implementation of the buddy system will involve CRs working with an identified partner CR. A requirement of paid supervision will be that contact between partner CRs has occurred. This contact is where much support within the team is expected to occur.

PRESENTING & PUBLISHING

Presenting at Conferences

Before you present at a conference – you usually need to submit an abstract or your presentation to the conference organisers.

- An abstract is a short description of your presentation – usually the organisers will give you an idea of the size limit. Often it will be between 50 and 150 words.

Details about what the conference organisers require are usually provided in the “Call for Papers” which occurs some months before the conference.

It is OK if your final presentation differs slightly from the abstract you submitted, however most conference organisers will expect that the abstract reflects the presentation.

The most important thing is to make sure you feel prepared for the presentation.

“The Kit” (1999) provides us with some good guides about presenting:

Prepare your message by considering:

- What do you want to say?
  Spend time making this really clear for yourself, and it will then help you make this very clear to your audience.

- Who is your audience?
  Who you are presenting to will effect the way you present – how you pitch it. For example, if you are talking to people who have no experience with a mental health service, or consumer issues, you will have to explain concepts and terms that an audience of consumers or carers might already understand well.

- What is the purpose of your message?
  Consider carefully what you hope to achieve in your presentation – are you looking for support? Are you hoping to get people thinking? Are you trying to convey facts?

What is the best way to get your message across?

Things to think about include:

- How formal or informal do you want your presentation to be?

- Do you want your presentation to be interactive – with the audience taking part in some way?

- What aids do you need to present well?
  Using **Visual Aids** can really help some audience members understand and remember what you are talking about. They can also be helpful for you as a presenter – they help structure and give you something to refer to.

  Other types of aids might be resources from other areas – like a powerful quotation you have found, or a story or anecdote that helps highlight your main point.

Some tips for using visual aids:

Whatever type of visual aid you use, there are some important things to remember when you prepare them:

- Make sure/check that what you have prepared is easy to read – think about it from an audience member perspective.

- Put only a few points on any page – whether you use an overhead or PowerPoint presentation, or a whiteboard. Too much information/writing will make it hard to read. **Use the aid to make your main points.**

- Make the language clear and simple

- If you're using **overheads**, use dark coloured marker pens – these make it easier to read.

- If you're preparing a **PowerPoint presentation**, usually a dark coloured background with light coloured writing is easiest for the audience to look at and read.

- Pictures can be a powerful way to convey a message – and give your audience a break from reading.

Some general tips for presentations:

- Eye contact is powerful – it helps you connect with the audience. It also helps your voice carry so you can be heard well.

- If you are in a large room and a microphone is offered – use it, otherwise people may not be able to hear you speak.

- Do not rush your speech. People will not be able to follow you well if you talk quickly – they may not be able to understand your presentation or remember it then.

- Use notes if you need to. If you do use notes, make sure you practise with them. Check that they are easy for you to follow, and help you present well, rather than confusing you. When you present, it's helpful to put your notes on a stand or table. If you are feeling nervous and hold your notes in your hand, it may make any shaking more evident – which might make you more nervous!

- Remember to let your audience know what you want from them. If you want them to ask questions at the end, leave time for this and tell them at the beginning. That way they know what to do.

- Have a glass of water handy – you might find you get a dry mouth from nerves or just the talking.

- Aim at addressing about 3 main points in your presentation – then make sure you emphasise these. This is where using overheads, whiteboards, etc. can be useful.

Publishing – Conference proceedings & Journals

Papers for publication will look different depending on what you are writing about. Usually a paper that is discussing research you have conducted will include the sections outlined below:

- **Title**
  You need to give your paper a title. The title should be brief and specific, yet descriptive of what you are writing about. The title needs to include imprtant key words with consideration of electronic database searching in mind.

- **Abstract**
  An abstract is a short overview of what your paper says. Usually an abstract is between 50 – 100 words. Some journals or conferences may ask for an abstract of a specific length – or with a specific limit.

  Often it is best to write this once you have finished the paper.

- **Introduction**
  In this section of the paper, you outline what you are writing about.

  In the introduction you need to:

  - review any other literature about the topic, write about how this makes sense to you, if you think there are gaps in what has already been written. You would also discuss how you make sense of what has been written by others;

  - discuss why you are writing about the topic – and why you conducted the research (for example, the research might not have been conducted before, or it might have been done in other countries, and never in Australia);

  - outline the aims of your research – or the aims of your paper. Sometimes you might be making hypotheses (that is, you can say that you anticipate certain things to be the outcome of the research), sometimes you may have aims. This is usually done as the last section of the introduction.

Whenever you write about something that you have read – or when ever you refer to someone else's work – you must cite where you got your information.
This involves noting the author and date in the text, and then including the full reference in your reference list. To note a reference in the text you can do one of 2 things:

1. eg: Polgar and Thomas (1995) discuss sampling methods in research and suggest that to conduct random sampling a method such as a random numbers table be used.
2. eg: It is suggested that a random numbers table be used to when adopting a random sampling method (Polgar & Thomas, 1995).

- **Method**

The method section of the paper discusses how you conducted the research. It is important to remember **you need to include enough detail to enable another researcher to replicate your investigation.** You need to discuss:

- Who participated – outlining some general description of the participants as a group. For example, you would usually note the gender mix of the group, age ranges of participants etc.
- How you recruited participants.
- What sort of data collection you used - (eg: interviews, questionnaires etc). You need to explain what this involved.
- How you plan to analyse the information you receive.

- **Results**

This is where you discuss what you found - the results of your analysis of the information collected.

- **Discussion**

In the discussion section, you talk further about the results.

- You begin to make interpretations and draw conclusions about your findings.
- You need to link the findings back to what you were writing in the introduction.
- Explain how the findings add to/ change/ make sense of what other's have written.
- Evaluate your aims or hypotheses in terms of what you have found.
- In this section you also need to talk about what you suggest other's do differently – what didn't work so well, or as you expected?

- **References**

This section of the paper lists all the other sources you have used to write the paper. These are listed in alphabetical order, and generally you need to follow a specific style in writing this section. Each reference should follow the following format:

<u>If the reference is a journal article</u>:

Authors name. (date of publication). Title of article. *Title of Journal. Number of the volume of journal,* page numbers of article.

For example:

Smith, J. (1998). The best way to write a journal article. *Research Methods and Writing, 11,* 79-84.

If the reference is a book:

Authors name. (date of publication). *Title of Book.* Publisher, city/country

For example:
Polgar, S & Thomas, S. (1995). *Introduction to research in the health sciences 3rd Edition.* Churchill Livingstone, Melbourne.

Different referencing systems are used, however this is the type of referencing system used by most psychology journals. **It is important to check what referencing system is used by a journal you want to submit to.**

In a research paper, you use the section headings above in your paper. The only section you do not title is the introduction. So, you title the Method section, the Results section, and so on, with these names.

If you are writing a discussion paper, it will only include some of these sections. Usually it will still have an abstract, an introduction, and most of the paper will then be discussion. You usually won't use these labels as titles for the sections, but write titles that reflect the content.

If you want to try and publish your writing there are a few things that you need to consider:

- Where do you want your work published? You may have different options to consider. If you have presented the same work at a conference, you may have an opportunity to submit a written version to go into the conference proceedings. There are many journals where work can be published also. Like when preparing a presentation – you need to consider whom your audience will be when writing too.

- When writing to submit to conference proceedings or a journal you will usually be required to set your work out in a particular way. Different conference committees and journal editors may have slightly different requirements. These might include things like word count or size of the paper, the font you need to use, how many copies you need to submit etc. You can find these requirements:
  1) for conferences by asking the conference organisers – or sometimes checking on the conference website; or 2) for journals, usually each copy of the journal has a list of submission requirements at the back of the copy.

Tips for writing a paper for publication:

- Like presentations, you need to make sure your writing is easy for people to understand and follow. Keep it clear and simple.

- Decide on your argument and make sure you follow this through in writing the paper – keep coming back to your major points.

- Read through and check your writing often. Taking a break from writing and then coming back to it and reading it can help you find mistakes you couldn't see before.

- Having someone else proof read your writing is always useful. Someone else doesn't know what you are trying to say like you do. This is a useful way to see if you actually are saying what you want to.

- If you use terms that aren't generally understood – or are specific to an area – make sure you explain what you mean. Getting someone else to proofread the paper is useful for this – they can let you know if you have used terms that they don't understand.

- Expect to write a few drafts.

Some ethical considerations when publishing and presenting

- If you mention other people in a presentation or a written paper, you need to get their permission. Ideally, they should see a copy of what you are going to say, or what you have written before it is presented or published.

If you are representing a group, it is usually advisable to make sure you discuss your presentation with the group – this helps make sure the group you are presenting a shared understanding in your talk or writing.

References & Further Reading: Presenting and Publishing

Commonwealth Department of Health and Family Services. (1999). *The Kit: A guide to the advocacy we choose to do. A resource kit for consumers of mental health services and family carers.* Spice Consulting, Australia

O'Shea, R. (2000). *Writing for psychology: an introductory guide for students.* Harcourt Brace, Sydney

Appendix 2: Background articles

Gill, K., Pratt, C., & Librera, L. (1998). The effects of consumer vs. staff administration on the measurement of consumer satisfaction with psychiatric rehabilitation. *Psychiatric Rehabilitation Journal, 21,* 365-370.

Lecomte, T., Wilde, J., & Wallace, C. (1999). Mental health consumers as peer interviewers. *Psychiatric Services, 50,* 693-695.

Oades L., Viney, L., Wong, E., Bowker, C., & Strang, J. (1999). *Promoting consumers' participation as mental health researchers.* Paper presented at Mental Health Services Conference, Melbourne.

APPENDIX 2:

TIMELINE OF CEO-MHS PROJECT MILESTONES

Timeframe	Activity
1999- 2001	Meeting of Consumer-Directed Research Group
Oct 2000	Australian Research Council Grant Approved
Feb 2001	Information session about the project in Nowra
May 2001	Appointment of APAI PhD Student Scholarship
June 2001	Workshop with Consumers and Management team to launch project
July 2001	Information session about the project in Wollongong
July – August 2001	Recruitment of Consumer Researchers
September 2001	Three day training session for Consumer Researchers
November – Dec 2001	Conducted 7 focus groups in Wollongong and Nowra
Dec 2001 – April 2002	Thematic analysis of focus group discussions
January – May 2002	Consumer validation of thematic analysis
May – July 2002	Development of interview questions and interview guide
June – July 2002	Additional training for CRs in interviewing skills
July 2002	Training in Power Point presentations for CRs
August 2002	Commencement of Interviews
January 2003	Workshop on “Writing for Publication” held
January 2003	Analysis of Interview Data commences
January 2003	Website Development commences
February – March 2003	Workshops help on developing the Evaluation Framework’

APPENDIX 3:

SELECTION CRITERIA FOR CONSUMER RESEARCHERS

Essential:

1. People who have gained expertise from direct experience of mental/emotional distress who have used area mental health services
2. Good communication skills
3. Good listening skills
4. Good translator into understandable language
5. Confidence to meet new people and willingness to undertake training in research skills.

Desirable:

An appreciation of the role of consumer participation in mental health service evaluation.

APPENDIX 4:

CEO-MHS INTERVIEW GUIDE - QUESTIONS

- Can you tell me about your experience of the Mental Health Services that have been provided for you, the good and the bad?

Prompts/ Probes:

- What do you think about the quality of care you usually receive from health professionals?
- What about the quality of the different types of services such as the crisis team, in-patient, out-patient or other services you have received?

- If you could have an ideal service, what would it be like?

Now I would like to ask you about some things that other people have said to see if these have or have not been important for you.

1 Some people have said isolation and a lack of community involvement was an issue for them. Has this been important for you?

  - What about negative perceptions or stigma?
  - Do you feel people have isolated you because of your mental illness?
  - What would alleviate your isolation? (only ask if the person states they feel isolated)
  - Do you think others don't understand what it is like to have a mental illness?

2 Some people have felt like they haven't had control over some aspects of their life due to their mental illness, have you had experiences of feeling like you had no power?

  - Can you tell me about times and situations when you felt either powerful or powerless?
  - Has this been an issue with health professionals?
  - What are your thoughts about how much control you have over your life when you are unwell?
  - At these times do you think the balance of power between you and health professionals is appropriate to your situation?
  - How do you cope with having a mental illness, both when you are functioning well and when you are in crisis?

3 Stigma is another issue for people who experience mental illness. People can feel devalued by other people as a result. Have you had any of these experiences? If so, where and with who have you experienced this and what was it like?

  - What about when you were unwell and receiving treatment?
  - Do you think this situation is changing?

4 Can you tell me how you feel or what you think about consumer involvement in the provision of mental health services? (eg as consumer reps, consumer rehab assistants etc)

- Is it important for you to have consumers involved in the provision of mental health services? If yes, what is it about consumer involvement that is important or unique?
- Can you tell me about any consumer involvement that has been important for you?

5 Receiving information and education about their particular mental illness and treatment has been important for some people. Has this been important for you?

- What would be the best way for you or others to receive this information?
- If this isn’t or hasn’t happened what do you think stops this?
- Do you think the general community (including those with mental illness) are adequately informed about mental illness? If not, what do you think ought to be done to better inform or educate people (including police, ambulance officers)?
- What do you think are the most important things for mental health staff to be educated about?

6 Many people spoke about their good and bad experiences with medication. Can you tell me about your experiences with medication?

- Do the negative side-effects of many of the current medications worry you?
- Can you tell me about how your medication helps you to cope with your mental illness?
- Do you have enough information about your medication and its side effects?

APPENDIX 5:

DISSEMINATION OF PROJECT FINDINGS

Book Chapters

Malins, G.L., Oades, L.G., & Viney, L.L (2003). Consuming Constructs: Why Are Mental Health Consumers Asked to Passively Consume Services? in G. Chiari and M. L. Nuzzo (Eds). *Psychological Constructivism and the Social World.* Milano, Angeli: EPCA Publications.

Journal Articles

Malins, G.L., Oades, L.G. & Viney, L.L. (2004). *What do Consumers want in a Mental Health Service?: An Analysis of Focus Group Discussions.*

- Targeting submission to Psychiatric Services.

Malins, G.L., Oades, L.G. & Viney, L.L. (2004). *What's in a service? Consumers' views of Australian mental health services.*

- targeting submission to Psychiatric Rehabilitation Journal.

Publications and Unpublished material

Malins, G. L., Morland, K. G., & Oades, L. G. (2002). *Consumer Evaluation of Mental Health Services: A training manual for consumers commencing research.* Illawarra Institute for Mental Health, University of Wollongong. Unpublished manual.

Morland, K., Malins, G., Strang, J., Dowson, T., Hunt, S., Williamson, D., Mason, M., & Eman, Y. (2004). *Towards Consumer Evaluation of Mental Health Services: A CEO-MHS Evaluation Framework.* Unpublished manuscript.

Viney, L. L., Oades, L. G., Lambert, W. G., & Strang, J. (2001). *Working with consumers to evaluate a mental health service.* A report for the Australian Research Council, Illawarra Area Mental Health Service & Illawarra Institute for Mental Health.

Conference Publications

Dowson, T. (2003). *Personal empowerment and involvement in the CEO-MHS project: Reflections of a consumer researcher.* Conference proceedings for the 13th Mental Health Services Conference of Australia and New Zealand, Canberra, Australia.

Hunt, S. & Williamson, D. (2003). *The experience of mental health consumers as* researchers conducting interviews with other mental health consumers. Conference proceedings for the 13th Mental Health Services Conference of Australia and New Zealand, Canberra, Australia.

Turner, J. A. & Sperling, J. (2003). A consumer perspective on collaboration during the consumer evaluation of mental health services project. Conference proceedings of the13th Mental Health Services Conference of Australia and New Zealand, Canberra, Australia.

Conference Presentations

November (2001) Presentation of CEO-MHS to Beverly Raphael, Director of the Centre for Mental Health.

Aspden, S., Malins, G., Oades, L.G., Viney, L.L & Champ, S. (2002). What do Consumers want in a Mental Health Service?: An Analysis of Focus Group Discussions. *Paper presented at TheMHS 12th Annual Mental Health Services* Conference, Sydney.

Hunt, S. & Dowson, T. (2004). *Turning the tide on evaluation in mental health services: Consumer Evaluation of Mental Health Services.* Paper presented at the NSW NGO Conference, Wollongong.

Malins, G.L., Champ, S., Oades, L.G., Viney, L.L., & Aspden, S. (2002, August). What do consumers want in a mental health service?: An analysis of focus group discussions. *The MHS 12th Annual Mental Health Services Conference, Sydney. Part of a symposium presentation titled: Consumer Evaluation of Mental Health Services: Not whether we should, but how we should.*

Malins, G.L. Oades, L.G., & Viney, L.L. (2002). *Consuming constructs: Why are mental health consumers asked to passively consume services?* Paper presented at the 6th European PCP Conference, Florence, Italy. Awarded the First European Personal Construct Psychology Doctoral Student Prize.

Malins, G.L., Oades, L.G., & Viney, L.L. (2002). *Modelling Mental Health Consumer Evaluation.* Paper presented at the 2002 Australasian Society for Psychiatric Research Conference, Canberra.

Malins, G. L., Oades, L. G., & Viney, L. L. (2002) Tuning in to the right wavelength: From models of evaluation to models of consumer evaluation of mental health services. Paper presented at the Illawarra Institute for Mental Health Conference November 2002

Malins, G.L., Oades, L.G., & Viney, L.L. (2003). *Developing a Model of the Processes by which Mental Health Consumers Become Researchers.* Paper presented at the 2003, XV International Congress on Personal Construct Psychology Huddersfield, UK.

Malins, G., Strang, J., Lambert, G., Eman, Y., Oades, L., Viney, L. L., & McKeehan, K. (2001). *Consumer Evaluation of Mental Health Services: Forging our future through evaluation.* Paper presented at NSW CAG: Forging Our Futures Conference, Sydney.

Oades, L.G., Hunt, S., Huntriss, D., Malins, G., & Viney, L.L. (2004). What do consumers want from a mental health service. Workshop presented at The Mental Health Services & Australian Infant, Child and Family Mental Health Association Conference, Gold Coast, Australia.

Strang, J. & Champ, S. (2001). *Consumer Evaluation of Mental Health Services project launch.* Workshop presented at the University of Wollongong?

Strang, J., Eman, Y., Oades, L. G., Viney, L. L., Lambert, W. G. & Malins. G. (2002). *CEO-MHS: There's no evaluation without consumer evaluation.* Paper presented at the The Mental Health Services Conference, Sydney.

Strang, J., Eman, Y., Viney, L. L., Oades, L., Lambert, G., McLeod, R., Malins, G., & McKeehan, K. (2001). *Consumer Evaluation of MHS: Working in Partnership to evaluate MHS.* Paper presented at the iiMH 2nd Annual Conference, Riding the Wave Together: Partnership in Service Delivery.

Paper presented by Jon Strang, Yvonne Eman, Tony Turner and 2 CRs'. theMHS 2002 Sydney, not published

<u>Project related Conference Publications</u>

Bentley, C., Viney, L. L., & Oades, L. (2003). *Identification of carers' standards for the evaluation of public mental health services: A Personal Construct Model.* Conference proceedings of the 13th Mental Health Services Conference of Australia and New Zealand, Canberra, Australia.