
# State-wide
# Consumer Consultation
## on Routine Consumer Outcome Measurement by Non-Government Organisations providing Mental Health Programs in New South Wales:

## Report of findings and recommendations

October 2006

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Jonine Penrose-Wall

Mental Health Coordinating Council of NSW
**Outcomes Through NGOs Initiative**
A program of the NSW Mental Health NGO Development Strategy

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Consumers and carers who volunteered their time to attend.

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Staff members and Consumer Advisors of Member NGOs, who encouraged and or assisted consumers to participate.

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## Participating NGOs

NSW Consumer Advisory Group on Mental Health Inc
ARAFMI Illawarra
Central Sydney CCC (by Email)
Inner City CCC
Uniting Care Parramatta
Richmond Fellowship (4 participants)
Neami South West Sydney (3 participants)
Justice Action (morning only)
Eating Disorder Foundation of NSW
Salvation Army Suicide Prevention Program
Club SPERANZA (3 participants)
Psychiatric Rehabilitation Association (PRA)
New Horizons Enterprises
Exodus Foundation
Consumer (Mental Health) Activity Network Inc (CAN) -(by post and a separate 3-hour face to face meeting with the facilitators)
Womens Incest Survivors Network Inc
Other Consumer Advocate involved in multiple NGOs but not disclosing which one she was representing
Other CCCs by email
Kaiyu (by telephone and postal participation – 3 participants)
Mental Health Coordinating Council Inc (facilitators & visiting staff and Board member)

'NGOs have saved my life, literally! NGOs may help me see the light when I'm straying down the rocky path of self-destruction. I don't use the word recovery because I haven't recovered. I monotonously get readmitted to hospital and suffer from psychotic symptoms regularly. What I prefer to say is that I have adapted my life to my mental illness; it's always sitting on my shoulder'.

Thank you MHCC for being investigatively helpful. Since, in future, NGOs will probably be providing many more mental health care programs, they need, of course, to monitor their own progress, at an individual and collective client and staff level.

(posted consumer comment)

(What advice do you have to workers in NGOs about how they offer outcome monitoring to consumers?)

'Please allow time and don't rush people through the process".

(I expect most from NGOs)…
'More time and human connection, and more attention to my individual needs'.

Why and when should NGOs use routine consumer outcome monitoring?

'As the people who know me best, they need to document this knowledge'….'they should use it in accommodation NGOs, mental health support groups and counselling services'.

(posted consumer comment)

# 1. Introduction

The Mental Health Coordinating Council's (MHCC) state-wide consumer consultation was held further to the MHCC discussion paper, *Mapping the Difference We Make: Non-Government organisation use of routine consumer outcome evaluation in providing mental health care in NSW* (Penrose-Wall, 2006). This paper considers the current status and future potential for routine consumer outcome monitoring by NGOs in NSW: that is, the monitoring in a systematic way, the mental health and related social outcomes (health status, risk factors, functioning and quality of life) for adult consumers when they use NGO services. The paper referred to this as 'routine consumer health outcome measurement' (RCOM) and asked three key questions:

- Could RCOM contribute to consumers and workers working better together to meet consumer needs?
- Longer term, could RCOM foster the improved design and quality of NGO mental health services in NSW? and
- Should NGOs apply a system of agreed routine outcome measurement as part of a sector-wide quality improvement and service development initiative?

Consulting with consumers about the use of RCOM in NSW NGOs was always considered a vital step in MHCCs Outcomes Through NGOs Initiative. Each member of the project team acknowledged the importance of a consumer voice on any decisions about how NGOs attempt to help consumers and evaluate their practice. In the document *Mapping the Difference we Make* (Penrose-Wall, 2006) it is acknowledged that consumer partnership needs to be central to the use of outcome measurement, therefore consumer consent around the issue needed to be sought.

The following document reports the method, findings and conclusions from a four-hour consultation held on the 29th of September in Sydney to invite consumers' views on NGOs potentially adopting a system of routine consumer health outcome monitoring. Four facilitators convened the day (MB, MK, JPW, AS) including the chair of the NSW Consumer Advisory Group on Mental Health (NSW CAG). Importantly this was a consultation of primary consumers many of whom are Australian leaders in the consumer movement. They have provided clear recommendations for ways forward.

## Aim and objectives

**Aim:** To listen to and be lead by consumers in relation to considering the introduction of routine consumer outcome monitoring in mental health programs of non-government organisations in NSW.

**Objectives:**

1. To determine whether consumers find the use of routine outcome measurement by NGOs to be appropriate for use in certain programs, and if so, which programs.

2. To scope the unexpected issues raised by consumers in relation to the use of routine outcome measurement by mental health NGOs.

3. To establish what consumers feel is important to measure in relation to assessing their mental health and their recovery.

4. To find out what consumers expect from NGOs in providing mental health programs, and how this expectation differs from that of other clinical mental health services.

5. To explore consumer consent and further comment regarding the *Mapping the Difference We Make* strategic recommendations (Discussion Paper).

# 2. Method

## 2.1 The decision to have a half day forum

The decision to have a State wide consumer consultation as an initial and significant component of the Outcomes Through NGOs Initiative was a unanimous one. Each member of the project team acknowledged the importance of consumer consent and agreement in order for MHCC to progress with routine consumer outcome monitoring. Consumer contribution and the need for a consumer voice were deemed vital for this initiative. We wanted consumers to openly express their views and opinions about the use of routine outcome measurement in NGO services.

## 2.2 Notifying consumers about the consultation

An invitation was distributed to all MHCC member organisations via mail, email and fax. The invitation asked NGOs to nominate consumers to represent their organisation. We had the intention of receiving personal contact details of these specific consumers so that we would then be able to directly contact each individual consumer ourselves. We believed that direct contact with consumers would have helped to inform and involve consumers in planning the day as well as allowing us to develop a more personal relationship with consumers. Many NGOs were hesitant to disclose any personal details of consumer advocates and consultants, and preferred for us to contact the consumers through their agency contacts. We were also keen for consumer service users to attend, and not just consumer board members, staff and consumer advocates.

## 2.3 Participant delegate pack

In addition to the invitation we formulated some 'Questions in Advance' to send out one week prior to the consumers who had responded to the invitation. These questions were distributed with the intent of informing the participants about the type of questions and topics that were going to be asked and discussed at the consultation. These questions gave consumers the opportunity to familiarise themselves with the content areas so that they could be adequately prepared for discussions on the day. The Questions in Advance Booklet was sent out as part of a delegate pack.

The agenda was devised collectively by the Outcomes Through NGOs team and NSW Consumer Advisory Group Chairperson, Social Worker and consumer consultant, Anna Saminsky.

The pack also included an Executive Summary copy of *Mapping the Difference We Make*. This was a 24-page booklet containing a conceptual framework for quality improvement in NGOs, the rationale for RCOM, and key strategic recommendations for State wide leadership of RCOM in NSW NGOs with mental health programs. *Mapping the Difference We Make* was a policy overview that was not written principally for consumers, but was intended for a wide stakeholder audience, policy makers and the Executives of NGO boards. A summary was given at the consultation, but reliance was upon the Questions in Advance booklet, rather than the Discussion Paper, to orient consumers to the issues.

## 2.4 Formulation of agenda and structure of the day

The Outcomes Through NGOs Initiative team wanted to work closely with a consumer leader to formulate the consultation, so we invited NSW CAG Chairperson, Social Worker and consumer consultant, Anna Saminsky, to help us structure the day. Anna became the chair for the day, opening the day and then participating throughout.

We chose to structure the consultation to be a combination of both small group activities and larger group discussions. We decided that it would be productive to break the participants up into four separate groups, which would then work together throughout the day. A speaker from each group

was then nominated to share the information gathered with the other participants at the end of each activity.

At the beginning of the consultation we asked all participants to individually answer a question sheet that was placed on their chair. These were questions 1 and 4 in the Questions in Advance booklet. We decided to ask consumers to answer these questions on their own as we were asking them to personally reflect on their own experiences. This allowed consumers to completely express themselves without feeling uncomfortable in front of others and to avoid the 'follow the leader' bias problem common in focus groups and public consultations. It also allowed the convenors to collect the information for this report.

Within the small groups participants were asked to discuss questions 2, 3, 5 and 6 from the Questions in Advance booklet. The answers were written up onto flip charts and displayed around the room. These flip charts were then also used to refer to when presenting the findings to the larger group.

The outcomes team wrote four fictional scenarios along with questions to accompany them (see Appendix 4). Each group was given one to discuss. Each scenario focused on a different type of NGO service, and were designed to find out which types of organisations consumers thought should or should not use routine outcome measures as well as what consumers thought was most important to measure in relation to a persons recovery within each of the organisations. The findings from these group discussions were also written onto butcher's paper and discussed with the larger group.

The large group discussions were facilitated so that consumers were able to voice their thoughts on any other related topics and to share their personal experiences with outcome measurement tools. The large group discussions were conversations and debates between consumers. The facilitation at regular intervals handed the control over the dialogue and offered the facilitation to leading consumers. At the lunch break the team invited lead consumer consultants to take the lead of the afternoon sessions, however consumers reported that they were happy with the consultation team to continue to facilitate.

The Questions in Advance booklet and the refection sheet are all provided in the appendices. The agenda for the day was as follows.

# Agenda for the consultation

| | |
|---|---|
| 9:45am | Arrival, Registration, Meet and Greet |
| 10:00am | **Welcome and introduction from a consumer perspective**<br>Anna Saminsky, Chairperson of NSW Mental Health Consumer Advisory Group (CAG) |
| 10:10am | **Personal Reflection: What does Recovery mean to you?**<br>Please write your ideas on the work sheet |
| 10:15am | **Aims and objectives, Show of Hands and Housekeeping**<br>Marika Burgess |
| 10:25am | **What expectations do consumers have of NGOs?**<br>What is different about NGOs? What do you value about NGOs? |
| 10:35am | **BREAK: Morning Tea** |
| 10:50am | **Unravelling the jargon on 'Health' outcomes**<br>Melissa Kym |
| 11:00am | **Unravelling the agenda: What other consumers have said**<br>Jonine Penrose-Wall |
| 11:20am | **Scenarios in discussion groups**<br>The story of Harry, Jack, Julie and Somala: Which NGO programs should use RCOM? What domains should be measured? |
| 11:40am | **Discussion Groups of 4 or more**<br>Now tell us about what areas you think are important for you to monitor. |
| 12:15pm | **Group sharing**<br>Spokesperson from each group to feedback to the group |
| 12:30pm | **BREAK: Lunch** |
| 1:20pm | **Other Issues**<br>Could include consumer views on Frequency of measurement; preferred tools; MHOAT; The Camberwell Assessment of Need; Risk assessment; or any other issues consumers wish to address |
| 1:40pm | **Summary and consumer resolution to MHCC**<br>Anna Saminsky, leading consumers and co-facilitators |
| 2:00pm | **Submission of "Bright Ideas" (how might NGOs improve quality of services?)**<br>**Draw of final (and best) Participation Prize** |

# 3. Speaker Presentations

The order of presentations followed the agenda.

## 3.1 Chairperson's opening: Welcome and Introduction

Chairperson of NSW Consumer Advisory Group on Mental Health, Ms Anna Saminski spoke also as a board member of, and on behalf of the Mental Health Co-ordinating Council. She welcomed participants and thanked them for attending.

Ms Saminski noted that she recognised that many of those present were familiar faces. She expressed confidence that those present would offer informed comment from years of experience as consumers using NGOs and advising on mental health service development and advocacy. She thanked the facilitators for preparing the day on what is a difficult topic.

Anna spoke of her personal experience in NGOs for around 21 years. She reflected on NGOs' potential to contribute in many different ways to the lives of consumers. Regarding the place of health outcome monitoring in mental health services more generally, Ms Saminski reminded those present of past systems of unaccountable clinical and other practices. She noted the long history in mental health services being critiqued by consumers who had had many negative experiences when seeking treatment from treatment-related services: public, private and GP services. Misdiagnosis, misinformation and poor outcomes were once common. Outcome monitoring in clinical mental health services is a potential way to guide treatment and inform the consumer of their condition over time. A number of personal stories were conveyed to open up debate as to whether there is a necessity, opportunity and utility in NGOs also adopting relevant ways and systems to routinely monitor consumer recovery over time.

## 3.2 Show of hands exercise

In order to gain insight into how knowledgeable participants were around the subject of outcome measurement, and to help break the ice, the convenors decided to carry out a show of hands. Marika Burgess facilitated the activity. Below are the results of the show of hands activity:

Table 1- Show of hands responses

| **Show of Hands Question** | **Number of Hands** | **%** |
|---|---|---|
| Who has heard of outcome measures? | 14 | 74% |
| Who has ever had a mental health professional ask them to fill in a K10 or any other health questionnaire? | 11 | 58% |
| Who has used a care plan in the public mental health system? | 2 | 10% |
| Who has ever used an Individual Service Plan (ISP)? | 5 | 26% |
| Who here is an official consumer consultant? | 9 | 47% |
| Who here is a carer? | 4 | 21% |
| Who is a service user who may have used or currently attends an NGO for mental health purposes? | 6 | 32% |
| Who is a founder, board member or committee member of an NGO? | 13 | 68% |

In addition to gaining an understanding of the participants' familiarity with outcome measurement as a topic, the activity gave regard to those attending, allowing them to inform us of whether they were official advocates, service users, board members of NGOs and so on.

(this page excludes emailed and posted consumer comment)

**Convenors' conclusions**

**Understanding the jargon of outcome monitoring may remain difficult even for very experienced consumer consultants who are highly exposed to outcome-related advisory processes. Furthermore, and as we expected, the language of outcome monitoring and 'mental health' programs and program processes cannot be assumed to be shared across groups of consumers using NGOs due to the diversity of NGO cultures and functions.**

**We noted that those present are reasonably experienced in having used a health questionnaire (Q2) previously. But they are relatively inexperienced in having assessments inform a care plan (10%) or ISP process (26%). This means that under half have had the opportunity of structured documented care from any provider, including NGOs. Therefore, they may not have personally experienced the benefit from outcome monitoring to inform a planned approach to helping them or to identifying what it is about the service that may need to be different to better meet the consumer's needs.**

**Nearly half the participants are in consumer leadership roles (some employment roles), only one third are current or past service users (of NGOs), however, most are consumer founders or managers (Committee or board of management) members of NGOs. Even in this experienced group, not all had heard of routine monitoring of recovery over time or outcome monitoring before.**

## 3.3'Unravelling the Jargon'

Melissa Kym provided the opportunity to clarify and define common terms used when discussing outcome measures. This was important so that everyone attending had clear definitions to work with. The over head with some of the key concepts is below. These were discussed in length to ensure that all participants were of the same understanding as to the key terms being used.

**Common Terms Used When Talking About Outcome Measurement**

**'**Health Outcome Tools', 'Outcome Tools' and 'Recovery Tools': Questionnaires or assessments with the purpose of helping you map your recovery with your clinician/worker.

**'**Domains Of Measurement': Areas of your life that you think need to be monitored during your recovery journey.

**'**Routine Consumer Outcome Measurement' (RCOM): Outcome tools and systems for consumers that are used on a regular basis as a way to map your recovery journey.

**'**MHOAT': A system used by New South Wales public mental health services to monitor a consumer's mental health. MHOAT has many components, some of these components are outcome tools, while other forms are a structured method for more general clinical assessment.

## 3.4 'Unravelling the Agenda': why outcomes?

Consultant, Jonine Penrose-Wall (JPW Results) who is coordinating the Outcomes Through NGOs Initiative for MHCC's NGO Development Strategy, provided the meeting with an overview of the strategic agenda being proposed by MHCC. MHCC proposes that NGOs adopt some form of agreed minimal routine consumer outcome monitoring as soon as practical and by 2007 (subject to agreement by consumers and Member organisations). Her presentation covered:

- Key justification for a health outcomes approach by NGOs.
- Key content/recommendations within 'Mapping the Difference We Make'.
- What earlier consumer consultations reported on outcome monitoring by other mental health services (included in 'Mapping the Difference We Make').
- Why consumer opinion was needed specific to NGO program contexts.
- What part the Outcomes Through NGOs Initiative will play.

The following are select overheads that were presented by Jonine.

### Discussion Paper Aim

To ask NGOs….

1. Could RCOM contribute to consumers and workers working better together to meet consumer needs?
2. Longer term, could RCOM foster the improved design and quality of NGO mental health services in NSW?
3. Should NGOs apply a system of agreed RCOM as part of a sector-wide quality improvement and service development initiative?

### Current RCOM – Australia

**10 yrs ago** – Victorian NGOs (PDRSS) psychiatric disability rehabilitation and Support Sector services volunteered to use a system of RCOM

**5 yrs ago** – All public mental health services mandated RCOM in Australia

**5 yrs ago**- NSW mandated MHOAT

**4 yrs ago** – Better Outcomes in Mental Health optional for 25,000 GPs

Private psychiatry and private hospitals use a system of agreed RCOM

## Current use of RCOM – NSW

*(refer Mapping the Difference We Make)*

**NSW** – No RCOM 'system' for all NGOs working in mental health

Multiple quality systems are mandated through various funding bodies, but no mandated RCOM

3.4% (n=5) of MHCC NGOs and 5% of direct service providing NGOs use validated outcome measures routinely.

27 NGOs (MHCC members) use formal self-developed needs assessments as a proxy for outcome monitoring.

## Why consult NSW NGO Consumers on RCOM

Most consultations were 5-10 yrs ago

Andrews et al 1994, Stedman et al 1997) National Mental Health Strategy reported Australia-wide consumer consultations that RCOM is acceptable to consumers.

In research, outcome measurement is acceptable to adults and young people with mental disorders.

Suicidal young people participated in outcome monitoring well under the National Youth Suicide Prevention Strategy, including in NGOs.

**Previous Consultations report….**

RCOM has been thought of as synonymous with consumer empowerment and participation by some consumer authors.

RCOM is central to service reform.

A tool to shape services to better respond to consumers' needs.

Promotes mental health literacy – common language about complex mental disorders and 'mental health'

VICSERV's submission to the Senate Select Committee on Mental Health (2006) advocates RCOM in NGOs.

**National Standards of Mental Health Services says …**

"Consumers and their carers receive a comprehensive, timely and accurate assessment and a regular review of progress….

All consumers are reviewed 3 monthly
…reviews must be continuous during contact with MH Service…

When client declines a service
When client requests a service
When consumer injures self /another
When involuntary patient
If no contact has happened for 3 months
When consumer exits service
When sustained decline is shown".

Jonine outlined key aspects of the Discussion Paper. She also noted her decision not to spell out the findings in detail from all other consultations with consumers so that they do not sway opinion into agreement with what has gone on before in other similar studies and consultations.

She invited consumers to share their views and experiences of how workers have presented or offered them the opportunity to appraise their own recovery using outcome tools, and to share stories of experience of when workers assessed their mental health using outcome tools.

Process issues were explored since these have been found lacking in previous consumer consultations. Previous consultations and comment from the floor confirmed that the objective or vision of MHOAT (RCOM in NSW Public Mental Health Services) to reform consumer and worker therapeutic interactions has not yet been fully achieved. MHOAT CCC participants made comments in agreement that more must be done in this regard.

Jonine restated the objective was not to focus on 'which tool', which has been the focus on some other consumer consultations. Instead, it was to ensure consent for MHCC to pursue with consumers the general direction of outcome monitoring as part of evaluation infrastructure its purpose is to better identify and help meet consumer needs and for eventual service development use by the NGOs when they analyse and use outcome data. She noted that numerous consumer-developed tools are in existence (eg AVON Mental Health Measure developed by MIND UK, with uptake in all services in Scotland) she suggested it was not necessary to re-invent new tools. Many scores of recovery measures have been developed and require further research and she noted that Victorian and New Zealand consumer-developed tools were underway.

She invited comment and suggestions about preferred tools if any. At the point, negative comment about HoNOS and K10 were given. Consumers reported not understanding the name of HoNOS measure (Health of the Nation Outcome Scale) when it is the health of the consumer being monitored. Jonine noted the HoNOS was developed to overcome some problems with other tools, its significance is that it covers multiple areas of a consumer's life rather than being a single domain measure.

The name of HoNOS makes clear that outcome tools can be used at the level of assessing the health of a population when the assessment results of the health status of individuals is aggregated. Outcome tools are used for individual, group, agency-wide and population measurement of health and related outcomes.

**National Mental Health Strategy:**

Andrews et al 1994:
Consumer identified their priorities:

- measure disability
- measure quality of life
- measure satisfaction with service
- measure symptoms
- narrow choice to 6 measures
- national wide pilot of best 6

Stedman et al 1997:

Not what, but how to implement RCOM

- Positively framed questions
- Range of alternative responses
- Culturally appropriate and language
- Over 'past week' how did you feel rather than past month
- Benefits were many for consumers

**New Zealand and Victorian more recent consultations**

Graham et al 2001: Victorians – focus is on question of the suitability in general of consumer-rated measures for long term use, not specific to NGOs' use.

- Dislike negativity of BASIS-32
- Focus is on a new measure synthesized from others
- Argue for consumer involvement with other stakeholders

New Zealand (2000) consumers are developing new measures.

None ask about NGO contexts, the focus of our consultation.

**Definitions**

RCOM
Repeat measures of consumer outcome taken as part of routing of the organisation and when staff and consumers aim to manage disease, disability or risk factors to meet the needs consumers have identified.

Screening
Use of outcome tools/ and assessment scales to detect health problems administered once to individuals within defined populations of risk, to refer for thorough assessment eg

- Domestic violence screening
- Depression screening
- Risk assessment for suicide ideation among those with mental illness

**Outcomes Through NGOs Initiative**

- Regional meetings of NGOs
- State-wide consumer consult
- Develop WWW resources
- In-depth costing via case study on implementation c/- PRA and MHCC state-wide

And

**'HOW AND NOW SITE VISITS'**

Free quality management consulting services on outcome monitoring & systems development to MHCC Member Organisations

Gather feedback from NGOs for MHCC on Discussion Paper

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# 4. Findings from consultation

## 4.1 Consumers' views on 'Recovery'

As an early part of the consultation, we wanted participants to express what recovery means to them personally. We had a folded piece of paper on each seat, and asked participants to either write or draw what recovery means to them. The answers were anonymous. they were very insightful, personal accounts of recovery. As experts of their own recovery, we wanted to use these responses to further interpret all findings from the consultation. RCOM is not about taking that away from them, but about helping consumers map their journey to recovery, that is, to monitor their health status, practical needs or goals or difficulties, disabilities and strengths over time. Over the following pages you will find the participants' expressions of what recovery means to them.

**Convenors' Interpretation**

**Every answer to this question was unique (as expected). Nonetheless, common themes did emerge: a sense of responsibility; being able to relate to others; and living with dignity among others. All responses helped the convenors to gain an insight into what recovery means for consumers today and how outcome tools need to be relevant to consumer recovery journeys.**

## What Does Recovery Mean To You?
## Participants reflect on what recovery means to them

"Learning to be responsible and accountable for me. Being comfortable with me in front of someone else. Being independent and resilient. Is a journey of self discovery."

"Ability and appreciation of seizing the day. Being present with the day, everyday."

"Recovery means having a sense of wellness, holistic in body, mind and spirit."

- "Being able to relate to others
- Feeling confident in one's own ability
- Understanding personal limitations
- Knowing that if you go down you can come up again and get back to doing what you want to do."

"Being able to participate in life and be in control of my own behaviour. Being able to research and help myself understand my illness."

As a carer, recovery from a phase of depression of my wife is very sudden. The first few words in the morning means that she is back to living a life. It no longer means that I can stay during all its hard work, I've got used to that. But beware mania may not be far off.

- "Achieving my goals
- Celebrating small and great achievements/steps
- Rights and responsibilities
- Self growth: Development, Esteem, Confidence = Empowerment
- Having friendships. Being loved. Loving others.

## What Does Recovery Mean To You?
## Participants reflect on what recovery means to them

"Recovery means remaining stable and functioning out of hospital and continuing to take my tablets and look after my mental health and well being."

"It means a good life for my self, living in the community and having a nice place to live."

"To live in this world not of this world".
The above statement is only one of many that ring true to me. These I have picked up as I continue to recover, and use almost on a daily basis. I will never be the same as I was and sometimes I am grateful for that. I feel "living with", rather than "recovering from" is more accurate. Everyone is "living with life".

"Recovery is being able to take personal control of my illness and subsequent treatment. From this my life becomes more settled and so belongs to ME. It is essential that I own and drive my own recovery."

"Recovery to me means functioning at my optimal level of functioning i.e.
- Being confident
- Being assertive
- Making good decisions
- Saving money
- Continuous personal growth
- Enjoying life
- Managing my mental illness and not letting it control me
- Keeping fit
- Having good relationships
- Having a good job
- Enjoying life"

"Get well, and feel confident. Involvement in community activity. Live like 'normal' live."

"A return to peace of mind. A return to day to day functioning. Acquisition of knowledge on the condition. Goals set to reduce the chance of re occurrence
Confidence in self."

## What Does Recovery Mean To You?
## Participants reflect on what recovery means to them

"The feeling of freedom-Escape-Bound up no more. It means that the incredible roller coaster journey of darkness, pain, insecurity, illness and dislocation is coming to an end. I can see my journey from a more peaceful, accepting perspective. It's wonderful to have clarity, sense of achievement and hope for the future. Old habits die hard but my new sense of control and freedom will take a lot to kill. You know what, "I feel like I'm coming home"."

"A journey of adjustment to an episodic illness, bi polar. Where at times I am more high functioning than at other times. Recovery is about not blaming anyone and no shame to myself, or anyone. It is about taking responsibility at those times when I am well for those times when I am unwell. Recovery is about accepting that I have highs and lows and agreeing to take medication."

"Get well, and feel confident. Involvement in community activity. Live like 'normal' live:

- Forgiveness of self and others.
- Dignity
- Connections
- Clarity
- Self regard
- A chance to grieve and to heal
- A chance to love
- Resilience
- Emergence of soul and spirit. I care about: I enjoy, I love, I have fun.
- To become myself, and to be in a place where I can ease the pain of others and provide hope."

"Recovery to me means a change from a life which is often unbearable and uncomfortable to a life which is either manageable or treatable."

"Recovery 90% of the time has been bad because of the attitude of nurses and doctors."

## 4.2 Consumers' views on NGOs and their Recovery

**NGOs And Your Recovery**

Do you think NGOs are **different** to other kinds of mental health services?

What do you **expect MOST** from going to an NGO-run mental health program?

**Answer:** NGOs are valued for their distinctiveness and empathy

We wanted to find out from participants what they expect most from their NGO to determine whether outcome tools could possibly help NGOs meet consumers' needs and expectations and to help determine which outcome tools are more appropriate. To do this, we asked consumers to divide into small groups and brainstorm, on flip charts, what they expect most from an NGO run mental health program.

We also wanted the participants to have it clear in their mind that we were discussing NGOs SPECIFICALLY, and not public mental health services, so we asked them to brainstorm if and how NGOs are different from other kinds of mental health services (eg. GP, case manager, private psychiatrist).

Within the five small groups consumers discussed these questions. The answers to these questions are presented on the following pages.

All consumers agreed when **some participants said that they expect a "professional service" from all NGOs.**

**Group 1**

Yes they are different. They

- Display empathy
- Friendly
- Understanding
- Available outside of business hours
- Add colour to the picture
- Give a lot more choice
- They know me the best

In NGOs, we expect:

- Have a more holistic approach
- Offer a non medical approach
- Have become more accountable
- Offer a sense of community and belonging
- An opportunity to socialise
- Mentoring

**Group 2**

Yes they are different. They

- See you as a person
- Support and help you eg banking help to manage your affairs
- NGOs are non judgemental, more accepting of who you are, where you are at

In NGOs, we expect:

- Individual planning
- Makes life more personalised
- Give us space
- Move you gently into recovery

**Group 3**

A little different

- You don't realistically get much say in an NGO
- Treated a little bit better by NGOs than by public health services
- Most NGOs can be more flexible in the way that they deliver services, therefore services more individualised
- Attitudes of staff generally better
- Different to private psychiatrist. Psychiatrist tried to fit me in a box

In NGOs, we expect:

- Supportive, flexible, user friendly services
- Consumer operated NGOs need to be considered in Australia
- Active listeners

**Group 4**

Nothing different

- Depends on the specific role of the NGO
- Sense of belonging is same
- NGOs can be more individualistic, more care
- In NGOs there is more maintenance and daily contact and follow up
- NGOs more inclined to achieve holistic health approach

**Group 5**

Yes they are different. They....

- Are more sympathetic
- Friendly
- Personal service
- Communicate on same level as consumer
- Initial fear of MH services, felt more comfortable to go to an NGO- fear public services because they may take over and lock up patient (particularly at first)

In NGOs, we expect:

- NGOs do have limited time and resources, and there are high expectations
- In emergency can see a consultant quicker than an NGO
- All NGOs should have a consumer representative/ consultant.

**Other (including postal)**

- Non-government organisations are member-run and member-owned. Give us the money and we will get the best results as NGO listen to their people!
- They provide more a wellbeing ear than my GP or psychiatrist can provide usually

In NGOs, we expect:

- That the service is responsive to the clients' needs and listens to the hopes and aspirations of the members while concentrating on the abilities and not on the disabilities. ie. The Strengths Model.
- I expect more time and human connection, and more attention to my individual needs.
- Even if I use MHOAT with public mental health services, NGOs should offer me outcome measures again because NGOs may have a more experience-based knowledge of my mental health. I expect (with NGOs) to clarify partnerships in my recovery and wellbeing.

## Summary

Participants saw NGOs as different from other mental health services in the following ways:

- more friendly;
- more empathic;
- better attitudes towards consumers; and
- commonly expected a more holistic, strengths-based and personal approach to consumers' recovery.

**Convenors' Interpretation**

**Consumers DO value NGOs as inherently different to other mental health services. This is important to take into consideration when MHCC discusses with NGOs what health outcome tools to implement, as we want NGOs to continue being seen as unique and adding value in consumers' lives, since the purpose of NGOs in society is to enrich life quality. NGOs should perhaps be wary if they wish to implement the same tools that are used in the NSW public mental health system alone since these may not capture the distinctiveness of service value to consumers.**

## 4.3 Consumers' views on "In Principle…"

**Key Question Of The Day**

In an ideal world, in a well-funded NGO, in principle, do you think NGOs should use one or more health outcome tools to help you monitor your own mental health and how it changes over time?

**Answer:** Majority agreement

Participants were asked for their key strategic consent, early on in the day, before much discussion around outcome measurement had occured. They were asked
"In an ideal world, in a well-funded NGO, in principle, do you think NGOs should use one or more health outcome tools to help you monitor your own mental health and how it changes over time?"
They were asked to tick Yes, No or Don't Know, and to identify why they chose that answer. This answer was anonymous.

Seventeen answers were received, of which thirteen agreed in principle. Some very comprehensive answers as to why they felt this way were also received. Here are the answers as to why NGOs should use health outcome tools to help consumers monitor their mental health:

*"Because we want to know if services are making a positive difference to consumers' well-being".*

*"Mutually beneficial to consumers and NGO… Recognition of consumers meeting goals adds to improvement".*

*"Helps to focus, guide where I want to go. When I am unwell, life is disorganised I cannot see anything good/positive in life. Being able to see how I am progressing in my journey increases my self esteem, confidence, growth, sense of self belief in recovery – and ability to continue on the recovery journey [to a] more successful, purposeful life".*

*"Anything that helps understanding of the problem".*

*"Yes because we need the external evaluation process to identify to identify and monitor things that we might not be aware of or might not know how to measure".*

*"The more help the better".*

*"To maximise the best possible outcome for recovery".*

*"So I can take responsibility and gain insight".*

*"Self determination for the person/client".*

*"To cover all stages of recovery".*

*"It allows for personalised service. It is a check that the NGO is providing a quality service. It would be excellent if they (the outcome tools) were consumer delivered".*

*"For some consumers it is difficult to recognise achievements and plan for the future. With the ability to plan comes the opportunity for success".*

Three of the seventeen consumers who responded didn't know whether to agree or disagree. Only one reason was given:

*"Yes, but provided it does not irritate me and uses <u>my</u> language".*

This seems to suggest that there are many reasons why consumers agree with RCOM. Only one condition was nominated about cautious agreement. This consultation helped MHCC identify many of these conditions/ concerns that consumers have around outcome tools.

One consumer (mailed comments) disagreed with NGOs using any type of consumer health outcome tools. A reason was not given as to why they disagreed. See Chapter 5.

**Convenors' Interpretation**

**We can conclude that most of the participants (most of whom are very senior and experienced consumer advocates with some representative functions across public and mental health services) are in favour of NGOs using health outcome tools to help consumers monitor their mental health. This is important for MHCC to know, because if consumers do not agree with this, then MHCC has no business encouraging NGOs to implement health outcome tools. This question was intentionally general, and we understand that just because they agree in principle, does not mean that they wish for outcome measures to be implemented in all NGOs, or even in all programs. Furthermore, the question did not probe consumer experience with worker-administered, interview-based use of outcome assessment. Thus we can conclude here, support for consumer self-assessment (consumers appraising their own mental health using systematic tools to do so) through NGOs. That is, our question did emphasise, "to help <u>you</u> monitor <u>your own mental health</u>", and by implication, if consumers were to be treated as true partners by NGO programs, they may also support worker-administered tools also being applied through NGOs, but our question was not framed in this way.**

## 4.4 Consumers' views on types of programs in which to adopt RCOM

**Outcome Measures in Different NGO Programs**

Should the **NGO** offer Julie, Jack, Harry and Somalia questionnaires, say each 3-4 months to routinely monitor their own mental health?

- Julie's Story: Julie has depression and is using a mental health specialist NGO employment agency;
- Jack's Story: Jack has schizophrenia and is in an accommodation service;
- Harry's Story: Harry was once an alcohol user and became institutionalized. He was then successfully placed in the community and is now ageing and lonely. He is now volunteering at a Clubhouse;
- Somalia's Story: Somalia had anorexia in her teens and is now attending a self-help group for anxiety and depression which never really went away.

(Refer to Appendix 4 for the full scenarios)

We asked consumers about what types of NGO-run programs they thought outcome measures were suitable for use in, and to identify the types of programs where outcome measures had no place. We thought that it would be helpful for the participants to discuss this using a scenario, so that the topic was not overwhelming, and then they might draw on their own experiences too.

Four small groups were formed, and each group had a different scenario to initiate discussion around the above program types. The groups were asked whether it was suitable for the NGO that their case study was about

to offer consumer health outcome monitoring. After a twenty-minute discussion they reported back.

In regards to the question, 'should the agency ask questions about their mental health routinely', participants considering Julie's and Jack's case studies agreed quite strongly. They felt that there was a definite place for RCOM in both employment agencies and accommodation services specific to mental health issues. Reasons included: that it is important for consumers of these types of services to have an opportunity to monitor how they are going; to help meet needs; and to help meet goals. Specific to Julie's scenario it was suggested that the agency should use the information gathered to find the most appropriate employment for her.

The discussion around Clubhouses using RCOM was somewhat more contentious. Some claimed that yes it is appropriate, because no one else is monitoring Harry's mental health, therefore it is important that the clubhouse does. But one participant pointed out that some club houses decline membership unless the consumer has support from another mental health service. One consumer believed that a clubhouse could offer RCOM to Harry, but Harry should have the right to refuse to use the tool. This is an important point, as it is not MHCC's nor its member NGOs' intention to impose RCOM on consumers. There should always be informed choice on whether to use it or not.

Finally, Somalia's case study generated much large group discussion. Many participants believed that there is no place for outcome monitoring in self help groups. They are for relaxation and self-expression, and it is up to Somalia what she shares with the group.

In the Somalia case study there was also mention of Edu-Link, a fictional program linked to the self help group that will help Somalia finish high school, as she dropped out of school due to her anorexia. One participant strongly opposed a service like this using health outcome measures, as education and mental health are two separate things. However, others felt that as mental health impacts on your study and education, that it really is appropriate for a service to be monitoring their consumers' mental health.

Although no real consensus was reached with regards to the Somalia case study, this segment of our consultation gave us a clearer idea of the NGO services in which RCOM is seen as appropriate by consumers, and where it is seen as imposing or inappropriate in services.

We acknowledge that our consultation is not a representative sample of mental health NGO consumers, so we cannot draw conclusions about how all consumers feel about health outcome tool use particular in NGO programs.

Table 2- Summary of findings regarding NGO programs

| **Consumer Journey** | **Type of NGO Program** | **Agree or Disagree with RCOM in this program** |
|---|---|---|
| Jack aged 30<br><br>Has schizophrenia. Has trouble finding suitable accommodation. Needs help with daily living tasks. | Accommodation service | AGREE |
| Julie aged 40<br><br>Has been diagnosed with major depression. Has been unemployed for 8 months. employment agency helping her find work | Mental health specialist<br>Employment agency | AGREE |
| Harry aged 65<br><br>Volunteer at clubhouse. Early life in institution, now living in the community. No longer qualifies as disabled enough for case management. | Clubhouse | DIVIDED – the division was more to do with the different kinds of Clubhouses in operation, rather than the value of RCOM for Harry. |
| Somalia aged 27<br><br>Survivor of adolescent anorexia nervosa but with residual recurring depression. Only sees psychiatrist once every 6 months. Sees Self Help program regularly. | Self help group<br><br>Supported Education | POTENTIALLY AGREE<br><br>DISAGREE – view was that supported education was not a role for NGOs at present in NSW. Consumers gave little comment about in-principle place of RCOM to supported education. |

**Convenors' Interpretation**

**More exploration is needed around this topic within NGOs themselves and with the service users attending NGO programs. One consumer particularly in favour of outcome tools expressed the crucial view that it should be offered often, but consumers reserve the right to deny participating on any occasion when offered the opportunity to complete a tool.**

**(The convenors were surprised that a consumer would consider that outcome tools were not voluntary).**

## 4.5 Consumers' views on 'Domains of Measurement'

What aspect of recovery is most important for NGOs to monitor (ask about)?

- Julie's Story- Julie has depression and is using a mental health specialist NGO employment agency;
- Jack's Story- Jack has schizophrenia and is in an accommodation service;
- Harry's Story- Harry was once an alcohol user and is now volunteering at a Club House;
- Somalia's Story- Somalia had anorexia in her teens, and is now attending a self-help group for anxiety and depression.

(refer to appendix 5 for the full scenarios)

To explore the question of what content domains should be captured in outcome tools used by NGOs, we again asked participants to discuss, in their small groups, the same four scenarios. We also supplied them with a list of common domains to prompt them in case the concept was foreign. Groups varied slightly in opinions about what to measure, but there were general trends across groups.

The majority of participants believed that functioning is important for a person experiencing mental health problems to monitor. Functioning for this purpose means the ability to perform various roles in order to maintain independence (Graham et al, 2001 p. 25-6). Functioning can be physical activity based or psychological based. Participants believed that monitoring functioning was important in NGOs such as employment agencies, accommodation and possibly clubhouses.

The monitoring, or rather, helping in the formulation of goals was deemed a vital domain, especially in accommodation NGOs and clubhouses. Participants felt that helping them monitor their goals in life would aid in their recovery. One group expressed that help in identifying *realistic* goals is

particularly essential, as goals that are realistic therefore achievable are very important to have.

What is interesting to note is that none of the small groups identified symptoms as an important area to monitor when attending a mental health NGO program. Indeed, there was some large group discussion around the tendency for both public and non government mental health services to focus too much on illness symptoms/ difficulties and not on strengths, goals, relationships etc. This view has also been echoed in other consumer consultations (Graham et al, 2001 p.27; Gordon et al, 2004 p. 69).

**Convenors' Interpretation**

**This was an insightful discussion, and it really did detail what participants think is important to monitor. Consumers stress the importance of NGOs using tools that focus on strengths and goals rather than only symptoms and deficits. Indeed, it was not spelled out the degree to which symptom monitoring had a place in NGOs. The meeting spent some time exploring the possible place of monitoring outcomes across a range of dimensions to help an NGO better know consumer needs, and second, to help the NGO improve their contribution to the overall health of consumers.**

## 4.6 Other issues raised

### Consumer Education

There was a valuable discussion around the need for consumer education in regards to outcome tools. Many participants believed that tools are not truly in the consumers' hands unless consumers are trained in how to use tools properly. If consumers and workers alike are more educated around health outcome tools, then outcome tools will potentially have more benefits for all parties.

### National Mental Health Standards in NGOs

There was some debate around the *National Standards of Mental Health Services* and other standards frameworks under which NGOs work. Several participants claimed that since the next generation of consumers do not necessarily know about the National Standards, the spirit of these Standards and the implementation of the Standards is beginning to slide. One participant saw outcome tools as a way of reinforcing dedication to these standards. Other consumers agreed that implementing the Standards need to be reinvigorated across all public and NGO mental health programs.

***Consumers support NGOs taking up the spirit of the National Standards for Mental Health Services, which requires thorough assessment and monitoring of consumers' needs and health in appropriate ways.***

## 4.7 When consumers may be at risk

**What about suicide risk detection: how should NGOs detect risks for some consumers?**

Answer: Wise to detect risks where possible in and beyond outcome monitoring programs and assessment tools.

In the open discussions about Julie, Harry, Jack and Somalia's situations, the meeting also explored:

- Should outcome tools contain items that would highlight risk symptoms or behaviours such as suicide ideation, prior suicide attempt or depression severity suggestive of risk for a suicide attempt in the near future?

- Should NGOs routinely appraise in some other way within assessment processes these aspects of mental health work with consumers?

In the case of Harry, the participants considered him a potential risk for suicide because he was lonely enough to seek out a Clubhouse, had not (for a long time) had contact with a mental health service through case management having long ago been deemed to be 'successfully living independently in the community'. Yet, Harry had a prior pattern of problematic alcohol use, had poor connections in the community even though he had community tenancy, was lonely and had had no mental health assessment for a long time. 'Harry was falling in the cracks' consumers reported. Older men with prior histories of mental disorders with substance use are a high-risk group for suicide. Even though he was 'volunteering' at the Clubhouse and not a 'service-user' as such, RCOM was considered a good opportunity to explore his needs if the Clubhouse was sensitive enough to realize his motivations for volunteering. Suicide risk was considered an important aspect underpinning all assessment.

The concept of **opportunistic prevention and screening** being afforded by some items on some outcomes tools was noted by the facilitator as being vital to meeting unmet need — that is, outcome tools can be administered strategically, or on occasions for screening, rather than routinely. They can also be used for screening if used routinely, depending on the purpose of the program. She explained that it is about a helping agency being willing to depart from their core business at times in order to extend their attention to unmet need. She posed for discussion: just because an NGO sees its work as 'non-clinical' does this mean, in your view, that the NGO should not be on the look out for clinical problems and needs were they to arise or not be met by clinical mental health services?

This discussion was prompted because consumers saw sharp distinctions between clinical mental health services and NGOs ('non-clinical'). The example of GPs routinely screening for domestic violence in women patients was an example of a GP extending his or her role in physical medicine, to explore with patients psychological and relationship safety, as opportunistic public (preventative) health care. In the same way, suicide risk is a key issue for all NGOs to screen for, regardless of their specific program role, and it is sometimes an item within recommended tools for routine health outcome monitoring regardless of the 'clinical' 'non-clinical' distinctions made between organisations.

The facilitator asked for comment from the NGOs present that are specialists in suicide prevention, Suicide Prevention Australia, Salvation Army and Club SPERANZA. Envoy Alan Stains and Mr Tony Humphrey (Founder of SPERANZA and co-founder of SPA) and other SPERANZA participants endorsed the idea that NGOs should include risk assessment routinely if at all possible.

That consumers are referred to HASI (NGO) accommodation programs and to NGOs when still sub-acute was discussed as heightening the need for this to be included, but in a way that is therapeutic and sensitive.

The discussion generally supported the idea that while NGOs should not go overboard on risk management, safety was a key quality domain for all programs and that NGOs should attempt to structure risk assessment into their interviews and tools used in consumer assessment and consumer self-assessment.

# 5. Posted and phone consultation

## 5.1 Some quotes in the consultation

*I value NGOs because.... "I can forget the fact I have a mental illness. Reinforce I'm a person first, a community member second, and have a life of my choosing".*

*"My perspective is that it is NEVER appropriate for an NGO or a mental health service to be undertaking the monitoring of a person's mental health wellbeing. It is the consumer who needs to be enabled and supported to undertake this, rather than the reverse'.*

Consumers are virtually 'outcomed' to death! What consumers' don't receive is the 'normalacy' of living with a mental illness and living within the general community. Consumers are more than capable of determining and measuring their own outcomes when they choose to do so.

*The HoNOS (Health of the Nation Outcome Scale) has a dumb name. It is annoying to fill in a form with a stupid name. When I am sick, I can't think about the 'health of the nation', I can only think about my own mental health!*

## 5.2 Emailed, mailed and telephone consultation input

*WISN (Womens Incest Survivors Network) reported that NGOs have an obligation to look out for harms in their practices, models of counseling, other programs and workforces. RCOM can detect and measure harms as well as monitor what good outcomes are achieved.*

Consumer views and recommendations from written and telephone contributions will now be reported.

Apologies were received from 4 consumers who later provided mailed or telephoned or emailed comment. A group of other consumers (3 men) from Kaiyu had traveled from a regional town in NSW and had become delayed in arriving at the consultation on time. They too kindly posted their views to us.

Two further consumers emailed enquiries after the event to find out more about the consultation and how it went. One of these made a recommendation that the convenors explore some current research being undertaken by a Victorian study on RCOM (which we will do and appreciated). The same consumer has written a paper on RCOM (Holmes, 2003) and we located independently of his comments by email. We concluded from his correspondence and interest, general support for the directions proposed.

The other consumer is an active participant in MHOAT's NSW-Wide Consumer Consultative Committee. He expressed interest in the findings of the meeting.

Finally, another posted one was received 3 weeks after the event.

## 5.3 RCOM in NGOs to detect and prevent harms

Telephone consultation input provided to Jonine Penrose-Wall: A meeting was proposed by another consumer, Ms Maggie Lawson, who offered to extend the consultation in the Blue Mountains where a number of NGOs in mental health work together in community consultations and where consumers were willing to host their own meeting with the facilitators. This meeting was agreed and planned for November and is being jointly arranged by WISN, another MHCC member, Mountains Mental Health Community Resource Network and Jonine Penrose-Wall.

Representing WISN (Women's Incest Survivors Network), Maggie Lawson gave immediate comment for the purposes of this report. WISN proposed that routine consumer outcome monitoring, regardless of the focus of the outcome domains, was an agreed principle for WISN for counseling services and for NGOs providing 'service delivery' because it is a way of ensuring that unintended harms were detected from NGO interventions. This was of course subject to it being offered skillfully by trained workers and not being imposed. WISN does not itself provide such services but is an advocate group for consumers using services related to surviving sexual assault.

Ms Lawson gave the example of the vulnerability of women surviving adult impacts from childhood sexual assault and incest where battles with depression, anxiety, self harm and other mental disorders are common, but these may or may not be recognised by women or by the counseling agency. Further, she explained that not all counseling works with everyone in the same way and some people need counseling along with other approaches. RCOM is a way of ensuring the help given is effective and is not producing unknown-of harms or unintended exacerbation of symptoms because of the type of counseling or the areas explored with a woman in counseling at a particular point in time.

Finally, counseling could potentially be more short term for some people if effectiveness was monitored and the most effective models of approach were used. WISN also lobbies for the accreditation and registration of workers providing NGO counseling services to ensure the workforce is skilled and qualified to deliver counseling. WISN supports MHCC's directions in encouraging NGOs to adopt consumer-friendly routine consumer

outcome monitoring. WISN also noted the language of consumers using the public and NGO mental health services differ significantly to that in the womens health NGOs and feminist services. Nonetheless, WISN supports some systems development via MHCC for RCOM for the NGOs identifying in various ways with the mental health movement, broadly understood and that this may have to adopt different languages or concepts for different groups of NGOs relating to MHCC.

## 5.4 Consumer Activity Network Feedback

Ms Desley Casey, member of the Consumer Activity Network (CAN) provided apologies that she could not attend in person. She responded to the Questions in Advance Booklet. CAN is a primary consumer organisation and is an entirely consumer-led service delivery organisation with a focus on recovery activities and advocacy.

Ms Casey reported 8 meanings for 'recovery'. These are included in the early section of this reported.

About how NGOs are different to public sector and other mental health programs and of her expectations of them she reported:

- *"Yes, NGOs tend to be more community-focused.*
- *Less bureaucracy and red tape*
- *Consumer run services - as consumer in many respects provide more 'realistic' activities and connect more with the general community*
- *However, sometimes an NGO can take on aspects of a public mental health service by becoming and supporting 'they're a community' which in effects tends to become insular and wrap consumers up in the world of the NGO rather than the general community.*
- *'Clubhouses are a classic example of this, in many respects. They continually talk about the 'clubhouse community'.*
- *NGOs tend to be more proactive in monitoring and evaluating activities and adapting changes or providing other alternatives than the public health system.*
- *My GP looks after my physical health. My private psychiatrist looks after my mental health. Both undertake this in complete collaboration with me and neither talks to the other!!.*

- *One of the positive aspects of having a private psychiatrist is the stability of talking to a person who is in there for the long haul and not shifting on to undertaking other things, like care co-ordinators in the public system.*
- *Being part of CAN (Mental Health Inc) Consumer Activity Network is a very highly positive experience in the main, as it is completely non-clinical, run by consumers, and provides a range of opportunities to participate both within the organization and within the general community.*

In "What do you expect most from going to an NGO-run mental health program" CAN's contribution reported:

- "A non-clinical, non-linear focus, which is person-centred rather than organisational-centred.
- Community activities which interest me
- No being 'managed'.
- Forget the fact I have a mental illness. Reinforce I am a person first, a community member second, and have a life of my choosing".

Ms Casey went on to **disagree** with all other questions posed (see Appendix Questions in Advance Booklet'.

Given the extent of negative feedback on the remaining questions, yet the finding that Pitane Recovery Centre had a vision for recovery-orientated, voluntary, consumer self-assessment and was itself applying a system of what appeared to be a proxy for RCOM, the convenors asked if a face-to-face meeting was possible to share perspectives. A three-hour lunch meeting was a productive way to exchange understandings and to obtain Ms Casey's views in relation to Pitane Recovery Centre and consumer directed self-assessments. The meeting covered the following issues:

- What is a 'medical model' to Ms Casey and why did she think we were 'medicalising' consumer outcome monitoring?
- If not using outcome monitoring, how should NGOs demonstrate their worth? We explored how Ms Casey evaluates Pitane Recovery Centre activities, using or adapting the WRAP self-assessment surveys and we discussed its benefits and its limitations.
- The convenors clarified that they were not proposing the NGOs impose outcome monitoring on any program nor on any consumer

and we all agreed choice and consumers being in the driver's seat was paramount.

- The convenors were, on behalf of MHCC, also not proposing necessarily, a worker-administered system of outcome monitoring and indeed, value and promote the use of consumer-rated outcome tools where these are demonstrated in research as being of value for wider uptake.
- Which questions (language) seem to apply a medical tone to RCOM?
- How might NGOs adopt recovery-oriented outcome monitoring of some sort without consumers feeling 'outcomed-out!'?
- Since CAN was using WRAP outcome tool routinely, yet disagreed with NGOs using outcome tools at all (yet is itself and NGO and is using one), did CAN *really* disagree with what MHCC has proposed – that NGOs apply some kind of appropriate RCOM?

Indeed, this discussion confirmed that our problem was language, not disagreement on the fundamental question being put in the consultation. Ms Casey agreed with RCOM in principle, but has major concerns about how it might be approached and potentially mismanaged if it is not consumer-centred and involving of consumers in the governance of outcome monitoring when such systems are established by NGOs.

'*It's not just governance that they (consumers) sit on a committee, it's that the consumer has complete control of the out come measure in that it is a self direction outcome measure – does this make sense – different to clinicians or workers simply working with the person and saying fill it out and give it back to me*!'

The basis of forming these views was not Ms Casey's own experience of completing outcome tools with clinicians (since she has not had the need to used them), but that it is well-documented in policy evaluations, and consumers feedback of their experiences. She reported consumer views that the K10 use is reportedly poorly done by many workers in public mental health services where staff members view it as 'paper work' rather than an opportunity to enhance consumer control of their lives. It should be an opportunity for genuine dialogue take place with the consumer.

Further, the Questions in Advance booklet had been interpreted as over-'medicalising' (language) the issue and the debate, since an existing language of outcome monitoring had been used from prior studies and

prior consumer consultations (so as to not confuse the range of stakeholders about what in fact was being discussed).

## 5.5 Kaiyu Feedback

Three men who were to represent Kaiyu Clubhouse on the day did not end up attending due to extenuating circumstances. They sent apologies and responded to the Questions In Advance Booklet. Kaiyu is a Clubhouse located in Argenton, a regional town of NSW. It helps adults with a mental illness build skills, stamina and confidence in areas such as housing, day to day living and employment.

Their ideas of what recovery and NGOs means to them is included in the previous sections

When the Kaiyu representatives were asked for their key strategic consent through the question, 'in principle, do you think NGOs should use one or more health outcome tools to help you monitor your own mental health and how it changes over time?' Their answer was:

- 'Yes, because consistency of feedback to the bean counters (accountants) while retaining autonomy of the NGO'.

When asked to identify in which NGO mental health programs would it be appropriate to use outcome monitoring, Kaiyu representatives said:

- 'Progressive clubhouse model is the best that I have seen in Australia however this relies on adequate recurrent funding. Money in NSW is the big problem (See national mental health report)'.

They also felt that it is dependant on the size of the organisation, as 'paper work is a big burden on small organisations'.

The respondents were happy to either fill out outcome tools by themselves or by a worker, providing '*an information session explaining the purpose of the assessment' (w* as given by the worker). This view is consistent with those expressed in the consultation as previously reported.

The respondents shared their personal experiences of workers (in public mental health services) asking them to fill in an outcome tool, questionnaire, or health assessment form:

- *I left Hospital in a state as a protest did not fill in outcome tool.*
- *I left a lengthy complaints essay but did not have any response to matters raised. Will never use that service again.*

Many participants in our consultation had also had negative experiences with outcome tools used in clinical services. It is positive to see that consumers are still open minded about the use of RCOM in NGOs despite their unfortunate application by some services and some clinicians previously.

When asked, 'If you use a public mental health service (eg. Have an Area Mental Health case manager), should you be offered health outcome measurement again at the NGO?' The respondents said:

- *Yes, because as an ongoing measurement tool: 'Decline', 'No change', 'Improvement' and so on.*

The 3 male respondents completing the Questions ordered, from 1 to 10, what they thought were the most important domains of measurement.

1) Your practical needs (eg. housing, finances, child care)
2) Other health needs (eg. Help to stop smoking/lose weight)
3) How you rate your general physical health
4) Your relationships and sense of support from others
5) Your strengths/difficulties in doing things
6) Your interpersonal behaviour and skills (eg. Communication)
7) Your Knowledge about caring for your mental health? (eg. Knowledge of services, information about your medicines etc.)
8) Your safety at home or at the NGO (eg. From violence, safety when depressed or psychotic, safety from suicidal thoughts)
9) Adjustment and coping with mental illness in your life
10) General psychological wellbeing

The next three answers were really important for MHCC to have, as the consultation did not cover this area of data collection and pooling of data as we had hoped: Q: If information was collected from you about your mental health, would you feel OK about that being put into a database if a) kept confidential, and

b) if reports from the database were de-identified
c) if the NGO had you sign a specific consent about this?

- *Yes*

Do you believe that combining outcome data of all consumers using NGOs in NSW will lead to improvement of services?

- *Yes*

Would you agree to a state-wide pooling of data by MHCC that attempts to find deficiencies and improve services which is what Victorian NGOs in mental health have done since 1992?

- *Yes*

# 6. Discussion and Recommendations

## 6.1 Discussion of findings

To review, the key points that consumers made include:

- In principle, consumers who attend and provide governance and leadership to NGO mental health programs and services are in favour of NGOs using RCOM to assist the consumer and to assist the NGO in monitoring the consumer's mental health AND importantly, the related social outcomes important to consumer wellbeing such as leisure, housing status, income and employment, satisfaction with services and with life and so on.
- Participants value NGOs as inherently different to other mental health services.
- Consumers see a place for health outcome tools in some NGO programs, such as accommodation services employment agencies and clubhouses; were not sure about its place in self help programs and supported education. (Not all program types were put up for discussion).
- Consumers consulted with prefer tools that focus on strengths and goals rather than primarily on symptoms or deficits in functioning.
- Consumers consulted with expressed concerns about process issues about how workers would apply outcome tools therapeutically.
- Language and consumer-friendliness is important, not just in how the tools are worded, but in how a proposal about outcome monitoring is put to NGOs and consumers for consideration. Consumer involvement in these matters will give strength to program communications.

A shortcoming of the consultation, which may have affected the above findings, was the number of attendees. Of 144 member NGOs, 34 people sent RSVPs, and between 19 and 23 attended in total. Of these, 19 stayed for the entire duration of the consultation. We acknowledge that this is not an optimal sample of NSW NGO mental health consumers. Having said this, senior leaders in the field with a great deal of experience in local, state and national advocacy in mental health service development and service reform were in attendance and these same consumers have had important contributions made over many years to service development in NGOs as well. Thus, the group was an authoritative voice on the topic, and the context of NGO programs and services, notwithstanding the fact that more consumers will ideally be consulted over time, who are current service users of NGO programs. It was representative of leading opinions.

An additional constraint for the day was time. Outcome measurement is a complex subject matter, however more than a half day forum was deemed perhaps too much time. We did cover the intended material sufficiently during the half-day, but it may have been good to have had more open forum discussion between consumers.

Finally, and given that this was a 'first attempt' to consult on a complex topic, no attempt was made to specifically consult consumers from Aboriginal and Torres Strait Islander groups, nor from those who are from culturally and linguistically diverse groups within NSW. Effort to do so will be via site visits to NGOs and prior to the program venturing into these areas.

## 6.2 Findings compared with other consultations

While this consultation is unique in asking consumers about NGOs not public sector mental health 'treatment' contexts for outcome monitoring, the key findings from this consultation are broadly consistent with findings from other more recent consumer consultations around RCOM in other mental health settings and systems. They are also generally similar to those reported in the foundation documents, Andrews et al (1994) and Stedman et al (1997). Both of the latter processes reported national consultations (or field trials around the nation) with consumers (and other stakeholders) in which it was reported that consumers valued outcome monitoring as a mechanism for **public or private sector** mental health service reform but these reports were silent on NGO services and the unique context of NGO programmes. Prior consultations will now be discussed.

Building on **Andrews and colleagues** (1994) who short-listed preferred measures from the thousands available, and who elicited support from consumers that outcome monitoring would be desirable for service reform and feedback, **Stedman and colleagues** (1997) at the University of Queensland aimed to assess which measures were most feasible to use routinely in clinical practice for schizophrenia, mood disorders and anxiety disorders. They conducted consumer focus groups as a part of their larger project to field test six adult outcome measures in a range of private and public sector clinical practice settings (Stedman et al, 1997), excluding community organization-type NGOs (but including at least one private hospital). The key findings from these groups were:

- Participants supported the use of the tools.
- There is need for brevity, simplicity and comprehensiveness of what is measured.
- Measures are not the issue, the adequacy of the clinical processes of assessment and the process of outcome assessment did matter to consumers.
- Standardised training is required for the administration of measures.
- There remains need for more applied research into service effectiveness and the dimensions of consumer outcome.
- Consumers and professionals assessed needs differently: there was poor convergence between consumer and professional assessments. This shows how important it is for professionals to be informed by consumer views of their needs and priorities.

Mapping the Difference we make summarises these report further.

Other significant consumer consultations followed in the thick of implementing the directions laid down by Andrews et al and Stedman et al. For instance, **Graham and colleagues (2001)** reported the Consumer Consultation Project in Victoria which conducted a total of ten different consumer focus groups with 58 participants overall. These focus groups were designed and run as part of the Victorian Mental Health Outcomes Measurement Strategy: *Consumer Perspectives on Future Directions for Outcome Self-Assessment.* Their report concluded general support for the use of a consumer self-report instrument, and consumers see the process of such a tool as having the potential to contribute to the treatment that they

receive. Concerns were raised about the process of outcome measurement in the hands of clinicians:

- consumers were troubled by how they are approached for personal information,
- the use of consumer ratings in treatment planning (that is, if clinicians took any notice) and
- how outcome measurement is used to strengthen therapeutic dialogue (Graham et al, 2001p.1).

**Siggins Miller Consultants** then reported in October 2003 on consumer self-rated outcome measures in mental health. This study did a comparison between consumer self-reported measures of outcome. The objective was to quality improve what is on offer to consumers through outcome monitoring around Australia and to optimize consumers monitoring their own health actively. Authors included Dr Mary-Ellen Miller, Professor Ian Siggins, Associate Professor David Kavanagh and Dr Maria McDonald.

This study provides a literature review on consumer-self rating of mental health, an evaluation framework was developed including consultations across Australian States and Territories with consumers, clinicians and service providers again, in the public and private sectors and how they should apply consumer-completed tools. It was not limited to BASIS-32, Mental Health Inventory, K10, SF36, HoNOS, LSP, Role Functioning Scale but other additional tools. Finally, they recommended modification to tools as needed. In all, 96 consumers, 33 consumers of State CAGs, 47 State mental health officials and 35 carers were included. Its focus in consulting consumers was: what is the purpose, potential uses, and domains of outcome stakeholders believe most important SPECIFIC to self-rated, and self-reported outcome measures.

Importantly, this consultation clarified the literature and the content analysis of tools themselves to point out the differences between 'self administered, 'self-rated', and self-reported processes of consumers monitoring their own health (See glossary). While self-rated and self reported often mean the same thing, self reported' tools express 'yes' or 'no' to what functioning a consumer has (what they can and can't do), whereas consumer-rated tools focus on how a consumer 'feels' and rates themselves on a sliding scale as to what they 'feel' they can do and so on.

They report that Kessler et al (2000) use the term, 'consumer measures' as methods that do not require a clinical administration or clinical judgment'.

**Suffice it is here to say, that the convenors of the present MHCC consultation with consumers took into account the focus and questions asked in these prior consultation processes to inform what we should additionally ask consumers without repeating all the background that has been achieved by funded large-scale and multiple consumer consultation forums around the country. We also did not want to go over all old ground knowing that some consumers in attendance had participated in prior events and processes captured in these consultation processes.**

Nonetheless, ours was specific in a different way to all others held, that is, we asked **about NGO-delivered programs**, **consumer expectations of NGOs in contributing to the external facilitation of recovery, and ours was NSW specific,** thereby taking account of the integration of roles and service delivery contexts between systems of mental health care and broader community resources available to consumers.

Finally, **Gordon and colleagues (2004)** conducted a study in New Zealand on the development of a self assessed measure of consumer outcome for the New Zealand context (Gordon et al, 2004 p.1) replicating and adding to much of the Siggins Miller consultation findings.

As part of the Gordon et al studies they conducted five general consumer consultation meetings. Within these meetings consumers were asked to consider three tools. These tools had been chosen by a reference group who conducted extensive research in order to find acceptable measures to take to the consultations (Gordon et al, 2004 p.22). Their objective was explicit: to develop a new consumer completed tool, unlike our objective.

Consumers in Gordon's groups expressed a wide variety of views. Some of the key themes expressed by consumers across all the New Zealand consultation forums include:

- "People reported that feelings of hope, awareness of progress, and involvement in treatment were significantly associated with the process of self-assessment (Gordon et al, 2004 p.62)."

- "Participants were clear that a flexible approach needed to be adopted in relation to the completion of self-assessed outcome measures (Gordon et al, 2004 p.63).

- "Many participants expressed considerable trepidation about how information generated through self-assessed measures of consumer outcome would be used (Gordon et al, 2004 p.63)."

To conclude, the NSW NGO consultation reported here while small, did represent the largest networks of NGOs in NSW and heard from experienced consumer leaders in NSW mental health programs who are additionally experienced working across sectors in mental health. Findings did not depart from the overall support by consumers for the general direction of outcome monitoring becoming embedded into the program practices and training schedules of NGOs conducting mental health programs. Despite NGOs not providing 'treatment' for consumers, they provide other things of value to consumer recovery and consumers clearly believe that this work contributes to consumers' outcomes (problematic though it is to be clear of attribution in the case of interpreting all outcome monitoring data). Furthermore, NGOs provide the very things (broader things than treatment or control of 'symptoms') that prompted the outcome movement in the first place, which, by all the accounts we have referenced here and in *Mapping the Difference We Make*, were about attempts by a number of stakeholders to encourage a wider mandate for mental health treatment programs to work beyond symptoms. NGOs in mental health already do so, by providing accommodation support, social support and leisure programs, employment programs and other strengths-based interventions or opportunities. The question we asked was: would it be OK for NGOs too, to monitor with consumers outcomes relevant to NGO programs. Consumers confirmed in the affirmative (agreement).

## 6.3 Recommendations from consumer participants

This NSW Consumer Consultation on NGO use of RCOM made the following recommendations:

1. That NGOs and consumers and other stakeholders re-promote the need to implement the National Standards of Mental Health Services.

2. Consumers choosing to use health outcome tools should be adequately informed and educated around outcome measures by the primary care worker. That is, MHCC needs to ensure that NGOs educate consumers, and not just design outcome training that aims at helping workers to administer outcome tools. Consumers want to know more about how to use outcome tools themselves.

3. Consumers should:

- Be involved from the very beginning of outcome monitoring programs proposed by NGOs.
- Have the right to see completed outcome monitoring tools that workers might complete that assess the consumer's health.
- Have the opportunity to assist NGOs in the development of reporting forms (outcome tools) should new ones be needed.

4. All NGOs should have a designated consumer representative.

5. Outcome tools, if used by an NGO, should cover content relevant to integrating consumers back into the community. Tools should be quality of life, rather than symptoms based.

6. If possible, tools should be consumer-delivered: that is, NGOs could encourage consumer self-assessment where consumers appraise their own recovery over time, rather than workers doing so.

7. Tools should be administered by the primary care worker where the tools are completed by workers because it is sensitive information and should not be done in a peer-to-peer interaction.

8. Outcome tools, if used by an NGO, should not be an imposition on the service, it should blend into, and improve, the service.

9. Outcome tools are a choice for consumers and should never be imposed. Choices about the privacy of the information and data once collected is also about consumer choices being exercised.

A key recommendation from the **convenors** will be that paid consumer time is factored into the Outcomes Through NGOs Initiative including for consumer participation (at least 2 positions) on the Expert Reference Group for the Initiative.

While the Consumers' recommendations speak for themselves for the MHCC Board's consideration and for the information of and consideration by MHCC Member organisations, the convenors would like to express support for all the recommendations made by Consumers in this consultation process.

# Glossary

**'Consumer measures'** – Kessler (2000) uses this term for tools used by consumers or methods of outcome monitoring that do not require a clinical administration or clinical judgment' (Siggins Miller 2003). Sometimes the terms, 'consumer self-reported', 'consumer self-assessment', consumer self-rated' tools, or 'consumer-completed tools' are used to all mean that the staff member only needs to offer the opportunity for the consumer to complete the tool voluntarily, but the worker does not make a judgment about the consumers health or functioning.

**MHCC –** Mental Health Coordinating Council — the NSW NGO peak association for mental health NGOs. 144 NGOs are members.

**NGO** – Non-government organisations, including independent, not-for-profit associations and companies, Also called 'community organisations'.

**Major kinds of health outcomes in the NSW population**

- Mortality (eg death rates, suicide rates)
- Morbidity (suffering, disablement, pain)
- Wellbeing (eg sense of recovery, satisfaction with life)
- Satisfaction with the quality of services

**"Health" as it is used in the term 'health outcome' –'**Health' means different things to different people. In relation to 'health outcomes' it refers to many aspects of physical, mental (psychological and emotional), and spiritual wellbeing. Some people suggest it also means cultural wellbeing. By *health* outcome, we also mean:

- social outcomes (such as quality of relationships, support)
- sense of community
- employment satisfaction or status
- disability and changes in functioning
- problems or needs
- clinical outcomes such as number or severity of symptoms.

The World Health Organisation definition of health notes that positive functioning must be considered as well as deficits (WHO, as cited in Siggins Miller, 2003 p. 17)

**Health outcome (or health change over time) –** also called, 'consumer outcome': it means, over time, how is your physical and mental health progressing or changing or staying the same. It can include:

- wellbeing, strengths, skills, health knowledge
- 'disease'
- 'illness' (cause of disease is not known)
- 'symptoms'
- 'impairment'
- 'disability' or 'functioning'
- 'handicaps'
- 'risk or protective factors' for a disease

**Health Outcome Tool -** An assessment, questionnaires, or structured interview to monitor health change over time. K10 is one such tool.

**MHOAT** – the system of health files used by public mental health services. MHOAT is NOT an outcome tool, but uses outcome tools.

**Routine Consumer Outcome Measurement** – repeat measures of (health) outcome to manage disease, disability or risk factors.

**Self-rated measures** – A consumer self rated measure is a measure where consumers provide a rating for example from excellent to poor, whereas a self reporting measure has individuals providing a yes/no answer to a question.

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http://www.peu.unimelb.edu.au/publications/reports.html

**APPENDIX 1-**

# INVITATION: STATE-WIDE CONSUMER CONSULTATION

## "NGOs and consumer outcome measurement"

**Rozelle Hospital Conference Centre**
Date: Friday, 29th September
Time: 10am to 2pm
Wheelchair access: Please phone if you need wheelchair access so that we can make ramps available.

- Consumer chair Anna Saminsky, NSW CAG.
- Refreshments will be provided.
- By Car: Free Parking available.
- By Bus: Route 440 caught fom Central Railway Square; alight at Glover St Rozelle.
- The findings of the consultation will be recorded in an unidentified way to ensure confidentiality.

**RSVP by consumer name essential!**
RSVP by: Friday 15th September
The reason we need your name and address is to send you an agenda and outlining document prior to the consultation. This information will not be used or retained for any other purpose by MHCC.

**RSVP To: MHCC Outcomes for NGOs Program**

Phone: Melissa or Marika
(02) 9555 8388 ext 105
Fax: (02) 9810 8145
Mobile: Jonine 0409 741 414

***What is Outcome Measurement?***
Routine consumer outcome measurement is repeat measures of outcome taken when staff and consumers aim to manage disease, disability or risk factors or to meet the needs consumers have identified.

# WHAT THE CONSULTATION IS ABOUT

## IMPORTANCE OF CONSUMER INPUT

A (must read) MHCC Member discussion paper will be launched this month, *Mapping the Difference We Make: Non government organisation use of routine consumer outcome evaluation in providing mental health care in NSW*. The paper is for discussion by boards, management committees, managers, quality managers, consumer leaders and program coordinators and staff of NGOs.

The MHCC is beginning the program with a consumer consultation. We value the opinions of all consumers and believe that their input into this program is essential. This consultation will allow consumers to voice their thoughts on the topic of consumer outcome measurement.
All member NGOs of the MHCC are being cordially invited to be represented at the consultation by one or more consumer representatives. In order to get the most comprehensive view on the subject it would be greatly appreciated if at least one consumer representative from each organisation could attend. If carers wish to additionally attend, please let us know.

## EXAMPLES OF QUESTIONS WE WILL INVITE CONSUMERS TO ANSWER

- Do consumers want NGOs to offer outcome measurement routinely when they use services?
- Which NGO programs should use outcome measurement?
- Should NGOs offer the same or different measures to those used by public mental health services under MHOAT?
- Are there risks to an NGO if applying a system of outcome measurement?
- Do you have a personal experience of a worker asking you to fill in an outcome tool, questionnaire, assessment or form on your mental health?

The agenda for the consultation is still being formulated. We encourage consumers to contact us with any themes or issues around consumer outcome measurement which should be addressed.

## APPENDIX 2- Questions-In-Advance Booklet

FOR USE BY CONSUMERS OF NGO MENTAL HEALTH SERVICES: (FOR POST & EMAIL REPONSE FOR THOSE WHO COULD NOT ATTEND OUR STATE-WIDE CONSULTATION HELD 29 SEPT)

Email: jonine@iimetro.com.au OR project@mhcc.org.au
Post: MHCC Outcomes Through NGOs PO Box 668 Rozelle NSW 2039

# QUESTIONS-IN-ADVANCE

### Outcomes Through NGOs
### State-wide Mental Health Consumer Consultation for MHCC

on Routine Consumer Outcome Measurement by Non Government Organisations

Examples of what we are trying to find out

- Do you want to monitor your own recovery on a regular basis, say each 3-6 months?
- Do you think NGOs in mental health should offer you the tools to do so?
- If you participated in completing occasional short questionnaires about your recovery processes and outcomes, would that information help you and your key worker to better understand and meet your needs?
- How should NGOs monitor the worth of their programs?
- What sort of thing should NGO outcome monitoring focus upon and how should it differ from Mental Health clinical outcome monitoring such as that done in MHOAT?

**Introduction**

**Not all, and perhaps little, of a consumer's recovery is due to their attendance at a service or program. A lot of recovery is due to what the consumer does him/herself while using a service, and while helping themselves at home, or whilst just living out their lives. But human and health care services in many countries are adopting a 'outcomes' approach so that services learn to improve outcomes as distinct from just providing programs and activities. There is research evidence that suggests that NGOs achieve or facilitate quite different outcomes with and for consumers than clinical rehabilitation or clinical mental health services.**

This consultation aims to ask consumers **broad-brush questions** about what consumers expect of NGOs during their recovery journey and if they see recovery or health outcome monitoring by NGOs as appropriate generally speaking. You need not treat this as a

'survey', but more, a set of questions to stimulate a general response. But you may certainly answer specific questions where you can.

The questions are not about what sort of outcome monitoring tool you prefer to use. The questions are more about the bigger philosophical and practical expectations and priorities consumers have when they use an NGO mental health service.

It is not intended that outcome monitoring will in any way detract from NGOs having a **social view** of health and a holistic consumer-centred approach when providing external support for consumers in recovery. (Please see glossary last page).

## About your recovery and NGOs

**1.** What does "recovery" from a mental disorder or mental health problem mean to you?

**2.** NGOs run a lot of different kinds of programs, so the next question may be hard to answer. Do you think NGOs are **different** to other kinds of mental health service? For example, **do you experience** of them different kinds of help than say, how you are helped by your GP, your case manager, from going to hospital, or from a private psychiatrist?

**3.** What do you **expect MOST** from going to an NGO-run mental health program (i.e. that you don't necessarily expect from your GP, case manager, private psychiatrist or other service).

**NGOs and 'Health' Outcome Measurement**

**4**. **Public** mental health services have used routine consumer outcome measures (eg the 'K10') for 5 years. They do so when a person first goes to a mental health service, then again as treatment progresses, and again when the person leaves or changes a mental health service.

NGOs however are, for the most part, NON-MEDICAL and NON-CLINICAL services. They tend to focus on broad social health outcomes.

In an ideal world, in a well-funded NGO, **in principle**, do you think NGOs should also use one or more health outcome tools to help you monitor your own mental health (or recovery) and how your mental health may change over time?

YES ☐ WHY? _____

NO ☐ WHY? _____

DON'T KNOW ☐ WHY? _____

**5.** In **what kind of NGO mental health** programs would it be appropriate to monitor YOUR mental health over time?

(You may like to consider accommodation NGOs, work programs, information services, NGOs that provide counselling services, case management or residential or personal support, respite care, supported employment, clubhouse, self help group etc)

**6.** In which **NGO mental health programs** is it not appropriate? Why do you think this?

**7.** Some outcome tools are filled in by the consumer. Others are filled in by the key worker. Some tools are done together when the consumer tells the service what his or her needs or expectations or problems are.

- Would you prefer:

to fill it in yourself?

YES ☐ WHY? _____

for the worker to fill it in about you

Yes ☐ WHY? _____

to fill it in with a worker who is your key worker?

Yes ☐ WHY? _____

Technically and ethically, information about a consumer's health is personal and private information that belongs to the consumer. So if the worker fills it in about you, would you want to be informed of the findings and what the survey results mean?

YES ☐ WHY? _____

NO ☐ WHY? _____

DON'T KNOW ☐ WHY? _____

If you fill it in on your own, do you want the opportunity to discuss/ expand on your answers with the worker so the service can respond with different sorts of assistance? The other option is to do it at home in private as a personal reflection exercise only.

I want to discuss it with a key worker of my choice

YES ☐ WHY? _____

NO ☐ WHY? _____

DON'T KNOW ☐ WHY? _____

ANY OTHER COMMENTS?

**8. Do you have a personal experience** of a worker asking you to fill in an outcome tool, questionnaire, assessment or form on your mental health? (It can be positive or negative. It may have been at a GP or at a hospital or at a mental health service)

Given this experience, what advice do you have to workers in NGOs about how they offer outcome monitoring to consumers using NGO SERVICES?

**9.** If you use a public mental health service eg have an Area Mental Health case manager, should you be offered health outcome measurement **again** at the NGO if it was about different aspects of your health and mental health?

YES ☐ WHY? _____

NO ☐ WHY? _____

DON'T KNOW ☐ WHY? _____

**10. YOUR priorities for your recovery and what outcomes are most important to YOU to monitor over time:**

"Mental health" means a lot of different things to different people.

"Recovery" also means different things to different people.

Mental health outcome tools have been in development since at least the 1940s. They each explore quite different concepts depending on the era.

Some outcome tools ask about recovery concepts, while others ask about other concepts such as needs, goals, physical health, psychological functioning, distress, symptoms, levels of disability and so on. Others ask about satisfaction with services. Others focus on positive psychology ideas such as your aspirations, dreams, hopes or spirituality.

Here we are **NOT asking you what precise questions** we should include in a health outcome tool. Instead, we want to know in **general terms only**, what conceptual areas you think is most important to monitor about your recovery.

Out of each item on this list, whole outcome questionnaires could already exist or potentially be constructed.

QUESTION:

What ASPECTS IN GENERAL (or 'domains' of health) do you think **is most important to measure** for you to assess your mental health over time? Please list your **top 10** from 1 being most important to 10 being less important.

☐ **Symptoms including what symptoms you experience and their severity** (eg how depressed you feel, the nature of your thoughts, how often you cry?)

☐ Your **practical needs** (eg housing, finances, child care)

☐ Your **unmet needs**

☐ **Other health needs** (eg help to stop smoking/ lose weight)

☐ Your **goals in life**, and meeting your goals

☐ Extent of **emotional distress**

☐ How you rate your general **physical health**

☐ **Your relationships and** sense **of support** from others

☐ Your **safety at home or at the NGO** (eg from violence, safety when depressed or psychotic, safety from suicidal thoughts)

☐ Your **strengths**

☐ Your **difficulties** in doing things

☐ **Adjustment and coping** with mental illness in your life

☐ Your use of drugs or alcohol (if any) or problematic use

☐ **Employment** readiness, preferences or satisfaction

☐ Your interpersonal **behaviour** and skills (eg communication)

☐ **Your knowledge** about caring for your mental health? (eg knowledge of services, information about your medicines etc)

☐ **Disability** and functioning

☐ General psychological **wellbeing**

☐ **Other areas of life:**

_____

_____

**You may also prefer to nominate an outcome tool you know to be helpful.**

_____

_____

What kind of NGO services have you used. You may include more than one if you have used different services in the past (eg self help groups, clubhouse, etc).

_____

**11. PRIVACY and what USE is the information that is collected through routine consumer outcome measurement?**

Outcome tools generate a lot of data (information) about a consumer's health and recovery. The NGO is supposed to request permission from consumers to use this information to better meet the consumer's needs on a one-on-one basis with the consumer.

Outcome data can also be pooled, with consumer consent, and de-identified, into a database. The information can be retrieved into reports on the service and on the kinds of needs consumers express in that service as relevant to them. Reports may also be generated about how consumers generally feel when they first come to the service, over time, and when they leave the agency.

So, with outcome monitoring we can tell to some extent, how all consumers are doing or changing over time, when they are using one service or program or even a group of similar programs.

**QUESTION**

If information was collected from you about your mental health, would you feel OK about that being put into a database if

**a)** kept confidential, and
**b)** If reports from the database were personally de-identified?
**c)** If the NGO invited you to consider and sign a specific consent about this?

YES ☐ NO ☐ DON'T KNOW ☐

**12.** Do you believe that combining outcome data of all consumers using similar groups of NGOs in NSW could lead to improvement of sub groups of NGO services in a few years time?

YES ☐ NO ☐ DON'T KNOW ☐

**13.** Would you agree to a state-wide pooling of data by MHCC that attempts to find deficiencies and improve services? (Victorian NGOs in mental heath have done so since 1992?)

YES ☐ NO ☐ DON'T KNOW ☐

PLEASE FEEL FREE TO PROVIDE ANY FURTHER RECOMMENDATIONS OR COMMENT.

In appreciation for your consideration of these quite difficult questions.

# JARGON – OUR BRIEF GLOSSARY OF TERMS

**MHCC –** Mental Health Coordinating Council — the NSW NGO peak association for mental health NGOs. 144 NGOs are members.

**NGO** – Non government organisations, including independent, not-for-profit associations and companies, Also called 'community organisations'.

**Major kinds of health outcomes in the NSW population**

- Mortality (eg death rates, suicide rates)
- Morbidity (suffering, disablement, pain)
- Wellbeing (eg sense of recovery, satisfaction with life)
- Satisfaction with the quality of services

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- social outcomes (such as quality of relationships, support)
- sense of community
- employment satisfaction or status
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**Health outcome (or health change over time) –** also called, 'consumer outcome': it means, over time, how is your physical and mental health progressing or changing or staying the same. It can include:

- wellbeing, strengths, skills, health knowledge
- 'disease'
- 'illness' (cause of disease is not known)
- 'symptoms'
- 'impairment'
- 'disability' or 'functioning'
- 'handicaps'
- 'risk or protective factors' for a disease

**Health Outcome Tool -** An assessment, questionnaires, or structured interview to monitor health change over time. K10 is one such tool.

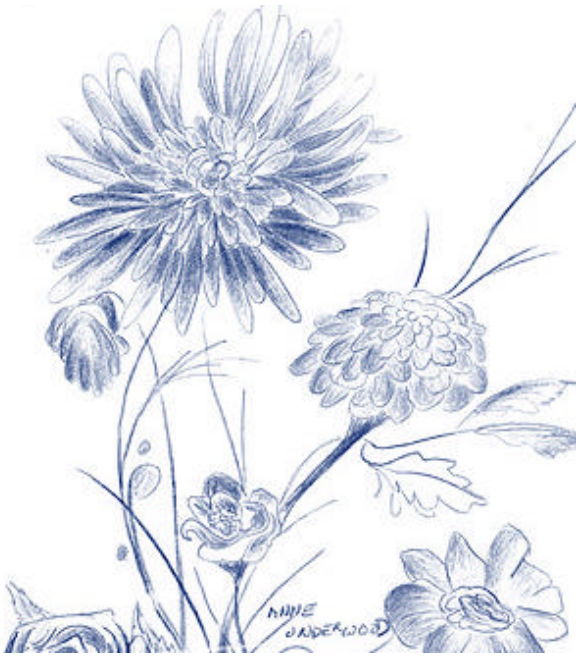
**MHOAT** – the system of health files used by public mental health services. MHOAT is NOT an outcome tool, but uses outcome tools.

**Routine Consumer Outcome Measurement** – repeat measures of (health) outcome to manage disease, disability or risk factors.

## APPENDIX 3- Recovery Worksheet

**What Does Recovery Mean To You?**

**A Personal Reflection**




Everyone's Journey of recovery is different. Please identify through words or drawings what recovery means to you personally.

This will help us to value how consumers experience recovery.

**Key Question Of The Day!**

Answer this question to go into the draw to win the Lucky Door Prize!!! Simply answer the question then tear of the bottom right corner and keep it safe!

In an ideal world, in a well-funded NGO, in principle, do you think NGOs should use one or more health outcome tools to help you monitor your own mental health and how it changes over time?

YES ☐ WHY? _____

NO ☐ WHY? _____

DON'T KNOW ☐ WHY? _____

(Note: Re formatted version- the original was designed to fold in half with the Recovery Question on the inside and the Key Question on the back)

# APPENDIX 4- Scenarios for Groups

## Harry's Story

Harry is 65 and lived at Gladesville Psychiatric Hospital for much of his adult life until it closed in the early 1990s. In the early days he had a serious alcohol problem but he was told years later, that he may not have ever had a mental illness, at least not such that he should have been in hospital all those years.

He now lives on his own. He never married.

For the first 10 years after leaving the hospital, Harry had to learn to do things for himself. He used to have a support worker from New Rainbows who came twice a week. Now he is too old to work, but no longer qualifies to get mental health services.

Harry is lonely. He recently started to attend a **Club House** run by Rainbow Fellowship. Mostly he goes there to see his old friends from the hospital and to volunteer to help those who are really affected by mental illness. Deep down, Harry is so lonely that he thinks he is actually developing mental health problems related to aging. The good thing about the Club House is that there is no pressure to get a job but you can still try your hand at a lot of worthwhile activity and help others there.

## Questions for discussion

1) Should **Rainbow Fellowship Club House** give Harry questionnaires, say at entry to the Club House to get to know him, and then, each 3-4 months to routinely monitor his mental health? If so why? If no, why?

2) What is it about Harry's recovery that is most important to monitor (or to ask him about)?
For example:

- Functioning
- Symptoms
- Employment skills or readiness
- Social confidence, self esteem
- Quality of Life
- His goals in life?
- His needs?

# Somalia's Story

Somalia is 27 and has a 4 year old son. Her hobbies are scrap booking and floral photography. She is married and lives in Fairfield in Western Sydney.

From age 14 Somalia had been in and out of treatment for anorexia nervosa including 4 major hospitalizations, each for over 8 months. These were life saving hospitalizations. Since the age of 21 she has had no hospitalisations but still sees a psychiatrist for a six monthly review. He checks her Body Mass Index and reviews any impacts of her years of starvation on her physical health. Her GP gives her supportive counselling also if she feels her old patterns of over-exercising starts up again. She only goes there if her son is sick, but the GP knows her and keeps a check on her in a supportive manner.

Somalia missed most of her high school because of the chronic starvation and lengthy hospitalizations. She lacks confidence and feels a failure compared to her girlfriends. She feels her underlying anxiety and depression were never completely resolved despite her weight gain and remission from anorexia.

Somalia attends a **monthly self-help group** for depression and anxiety because she used to find anorexia self help groups helpful when she was a teenager. She plans to go for at least 18 months. The self help group has a second program called Edu-Link, which raises funds to pay people with disabilities to catch up by doing their HSC as adults. They also provide a one on one tutor by phone or by home visit to guide the study. They help her develop study habits and give her structured ways of dealing with the anxiety.

## Questions for discussion

1) Should the **Self Help Group** give Somalia questionnaires, say each 3-4 months to routinely monitor her mental health? If so why? If no, why?

2) What about her recovery is most important to monitor (or to ask her about)? For example:

- Functioning as a parent.
- Symptoms.
- Social confidence, self esteem
- Quality of Life

3) What about Edu-Link? Should they monitor her mental health over the HSC year?

## Jack's Story

Jack is 30 years old. He has schizophrenia. He has trouble with finding suitable accommodation. Jack needs assistance with his day to day living and involvement in the community. He is looking for a service that provides medium term supported accommodation. Jack hopes that this service will give him the opportunity to develop the skills and confidence he needs to live independently.

The Green Park Independent Living Scheme provides:

- Medium term supported accommodation
- Assistance to access appropriate health and welfare services
- Flexible support programs which assist individuals with a range of issues such as: social support, transport, household management, budgeting, treatment management and assistance with daily living
- Assistance with locating and securing long term housing

## Questions for discussion

1) Should staff at Green Park routinely ask Jack questions about his mental health (for example every three months) while he is using the service?
Why/ Why not?

2) What about Jacks recovery is most important to monitor (ask about)?
For example:

- Functioning. What daily tasks do you find manageable or difficult, for example: maintaining your house, handling money and budgeting, cooking?
- Illness Symptoms. How do you rate your current situation in regard to: Memory, Depression, Level of concentration?
- Quality of Life. Level of your satisfaction with: Enjoyment of activities/life, Undertaking of meaningful work (paid/unpaid), Sense of self esteem and confidence?

3) Would your answers be different if Green Park Independent Scheme also ran a crisis accommodation program (refuge)?
Do outcome tools have a place in a crisis setting? Why/ Why not?

## Julie's Story

Julie is a 40 year old woman living with major depression. She used to work in a bank but was fired and has been unemployed for eight months. The depression seems to get worse with stress and she is having difficulty returning to the banking sector as a result. She is looking for completely new alternatives just to find any work at all and no longer knows what she wants to do with her life. She was referred to the Star Employment Agency* by Centrelink.

Star Employment is a Non Government Organisation that provides the following services:

- Personal and vocational rehabilitation and training
- Computer training
- Administrative skills training
- Resume preparation
- Support to retain the job when she does find a suitable work placement

Star Employment is happy to help Julie train for and look for employment.

## Questions For Discussion

1) Should staff at Star Employment ask Julie questions about her mental health routinely (for example every 3 months) while she is using the service?
Why/ Why not?

2) What about Julie's recovery is most important to monitor (ask about)?
For example:

- Quality of Life How satisfied are you with your life/ relationships/ accommodation conditions?)

- Functioning What daily tasks do you find easy or tricky- cooking, cleaning, getting to places on time?

- Symptoms of illness (How are you managing your anxiety levels/ depression levels/ memory?)

3) Would your answers be different if Star Employment was run as part of an informal clubhouse program? Do recovery tools have a place in a clubhouse setting? Why/ Why not?

## What aspects of (Harry, Jack, Somalia's or Julie's) Recovery should be monitored or assessed?

**Discuss and write up as a group.**

- ☐ **Symptoms / severity of your illness** (eg how depressed you feel, the nature of your thoughts, how often you cry?)
- ☐ Your **practical needs** (eg housing, finances, child care)
- ☐ Your **unmet needs**
- ☐ **Other health needs** (eg help to stop smoking/ lose weight)
- ☐ Your **goals in life**, and meeting your goals
- ☐ Extent of **emotional distress**
- ☐ How you rate your general **physical health**
- ☐ **Your relationships and** sense **of support** from others
- ☐ Your **safety at home or at the NGO** (eg from violence, safety when depressed or psychotic, safety from suicidal thoughts)
- ☐ Your **strengths/ difficulties** in doing things
- ☐ **Adjustment and coping** with mental illness in your life
- ☐ Your use of drugs or alcohol if any, or problematic use
- ☐ **Employment** readiness, preferences, satisfaction
- ☐ Your interpersonal **behaviour** and skills (eg communication)
- ☐ **Your knowledge** about caring for your mental health? (eg knowledge of services, information about your medicines etc)
- ☐ **Disability** and functioning
- ☐ General psychological **wellbeing**
- ☐ **Other:**