Promoting
Consumer Participation
in Mental Health Research:

A NATIONAL WORKSHOP

DEPRESSION
&
ANXIETY
CONSUMER
RESEARCH UNIT

CENTRE FOR MENTAL HEALTH RESEARCH

ANU

Promoting consumer participation in mental health research: A national workshop

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Acknowledgments

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Executive summary

There is increasing recognition both internationally and in Australia of the importance of active consumer involvement in mental health research. In 2001, the National Health & Medical Research Council (NHMRC) and the Consumers' Health Forum of Australia(CHF) released a *Statement on Consumer and Community Participation in Health and Medical Research* which acknowledges the benefit of and rights of consumers to participate in health research. However, the challenge will be to translate these in-principle recommendations into action.

In June, 2004 a national workshop was held in Canberra to consider how to promote increased consumer participation in mental health research. Delegates from a range of stakeholder backgrounds attended the workshop which was comprised of a series of lectures and workshop activities.

The Lectures

The workshop commenced with six background lectures. These were designed to provide policy perspectives on consumer participation in mental health research (*Casey; Northcott*), background information about stakeholder views about benefits, barriers and priorities for action to promote consumer participation in research (*Griffiths*) and models for active consumer involvement in research (*Epstein, Wadsworth; Micklethwaite*).

Dermot Casey, who at the time of the Workshop was the head of the Health Priorities and Suicide Prevention Branch, spoke of the importance of consumer involvement in health research and his hope that mental health might lead the way in developing paths for consumer involvement in health in general. Arguing

for the inclusion of consumer perspectives as a legitimate form of evidence, he observed that consumers 'need to be at the central heart of a research perspective'.

Suzanne Northcott, Executive Head of NHMRC's Centre for Research Management Head of the Research described the role of the NHMRC/CHF *Statement on Community Participation in Health and Medical Research* in the Council's strategic planning for the current triennium'. She noted that the NHMRC Research Committee has adopted six strategies for promoting consumer involvement. These are:

⊄# 'Expanding consumer representation on NHMRC Research Committee working groups

⊄# Commending the *Statement*

⊄# Providing information to consumers about the role of Research Committee and developing a network for information and support

⊄# Ensuring researchers support the rights of research participants to the results of the research and have access to their own results

⊄# Ensuring participation is part of good research practice

⊄# Monitoring implementation'

Future NHMRC grant applicants will be required to justify their research in terms of their dissemination strategies and plans for consumer involvement in the research. In addition, in the future, institutions accredited with the NHMRC will be required to comply with the NHMRC's new consumer statement.

In order to move the policy agenda forward, it is important to identify the benefits and barriers to consumer participation in health research and the means by which consumer participation might be promoted. *Kathy Griffiths*, Director of the Depression & Anxiety Consumer Research Unit at the Centre for Mental

Health Research at ANU, described the results of a survey that sought to identify stakeholder views about these matters. Identified advantages of consumer participation included *benefits to the research project* (contribution of important consumer expertise and a broader/different perspective; more relevant research; facilitating research and dissemination process; more ethical research, increased researcher accountability; increased value of research by consumers); *benefits to public health* (improved services and health outcomes); and *benefits to the consumer* (acknowledgment of consumer expertise, providing consumers with a sense of ownership and voice and an opportunity to contribute; destigmatisation). Perceived disadvantages of consumer participation related to *threats to the project* (lack of objectivity, project delays and lack of competence due to illness, lack of knowledge, lack of representativeness, increased costs), *threats to the consumer* (health and well being and financial/time costs) and *threats to the academic researcher* (time and status/control). Many respondents cited no disadvantage of consumer participation. Suggested priorities for action fell into six areas: *promoting awareness and cultural change*; *improving skills and knowledge*; *facilitating networking and communication*; and *establishing funding and resources*; *introducing evaluation processes*; and *developing policy*.

There are many models of consumer participation in research. *Merinda Epstein* and *Yoland Wadsworth* presented information about consumer driven research in mental health and *Beth Micklethwaite* described the implementation of consumer involvement in a researcher-led context.

In her presentation, *Merinda Epstein*'s emphasised that 'consumer perspective research is not just about adding a pinch of consumer to unchanged and unchallenged research assumptions, and stirring like mad. That cake will flop'. Rather, consumers can and do set the agenda and lead their own research. She argued that there is a need to rethink models of research funding and the research process and concepts of expertise and for consumers to educate non-consumer researchers about how to carry out ethical research involving consumers. Continuing the theme of consumer-driven research models, *Yoland Wadsworth* described her involvement as a non-consumer researcher with the

consumer led U&I project carried out in Victoria. She noted that key indicators for success for consumer driven research were a critical mass of consumers, independent resources and funding, and a 'consumer place' to return to in order to restrengthen the consumer perspective. However, she sounded a cautionary note in describing the premature end of what until then had been a very successful project: 'Everyone from the highest to the middle to the bottom of the entire system was literally coming along, agreeing to the next step. And at the end a bit of the wider system came in that went 'what? You are doing what?' 'You are employing consumers as staff consultants? Oh, we'll take that off you'. And they did.'

The final lecture was presented by *Beth Micklethwaite* and was concerned with a project designed to implement the *Statement on Consumer and Community Participation in Health and Medical Research* (2001). In contrast to the consumer driven model, this implementation model involved facilitating consumer participation at medical research institutions. The aims of the project, which is in its early stages, are to:

⫇# 'develop practical approaches to implement the statement at two pilot sites

⫇# produce a model framework for consumer participations in research

⫇# develop a resource pack to support consumer participation in research

⫇# evaluate the project.'

She reported some difficulty in finding willing organisations to participate in the project and emphasised the importance of tailoring implementation models to the local context. She noted that the aim is to involve consumers from the inception of a project and that a major task in the implementation process is 'the building of good relationships and a trust between the researchers and the consumers'.

Principles

Following a plenary discussion of issues raised during the background lectures, delegates worked in groups of eight to develop an aim and set of principles for consumer participation in mental health research. Delegates were provided with three sets of statements of principle including: a set derived from the vision and objectives set out in the NHMRC/CHF *Statement on Participation* (2001); a set developed by consensus methods at the University of Sheffield in the UK; and a set amalgamated by the workshop facilitator from the first two sets. Although there was not universal agreement within the groups, the delegates in three of the four groups were able to agree on a set of principles to be presented to the entire workshop.

After the presentation of the principles to the whole workshop by each group, it was proposed by the facilitator and agreed by the delegates that the first author of this report (KG) would integrate the four sets of principles into one coherent set of statements. In developing the final statements, KG attempted to preserve the intent underlying the original statements by each group and to take into account the issues raised in group discussions.

The resulting integrated draft aim and 11 principles are shown below:

Draft aim and principles for consumer participation in mental health research

Aim:

To improve the mental health of the community and expand and strengthen the current mental health knowledge base through increased consumer participation in mental health research.

Principles

1. The meaningful involvement of consumers at all stages of research including its conception, design, implementation, evaluation and dissemination will add value to the research.

2. The degree of consumer participation may reflect the degree to which the research impacts upon consumers.

3. Research partnerships involving consumers should be adaptable and based on understanding, respect, and shared commitment.

4. Each partnership will be sensitive to its research purposes and the expertise and experiences of the people involved and the environment in which it functions.

5. The roles and responsibilities of consumers and researchers will be clearly defined and agreed between those involved in the research and may evolve over time and the course of the project.

6. To fulfill their roles and responsibilities, both consumers and researchers need support and/or training to understand relevant aspects of research, ethics and each other's perspectives.

7. Budgets would appropriately include the cost of consumer involvement in research partnerships.

8. Resources should be provided to evaluate the research processes and contributions of consumer participation in order to foster continuing improvement of the implementation and benefits of consumer involvement.

9. Both consumer and researcher involvement will be acknowledged appropriately in research reports.

10. The results of research will be (1) made available to research participants in an appropriate and sensitive way; and (2) disseminated to relevant communities in a balanced and accessible manner.

11. Research organisations will have a policy on consumer participation in research.

Moving forward

The June 2004 workshop represents a first step towards developing a national agenda for promoting consumer participation in mental health research in Australia. The challenge now is to maintain the momentum established by this first workshop, to refine and implement its outcomes, and to develop targets and strategies for action. The workshop endorsed that continued work be undertaken by the Mental Health Council of Australia, beyondblue and the Dperession & Anxiety Consumer Research Unit at CRU to identify and plan ways of progressing the agenda quickly. The first task of the planning group will be to consider appropriate processes and structures for progressing the agenda and to identify, where needed, resources for supporting them.

A priority for the planning group will oversee the development of a final set of Principles from the draft principles summarized here. Conceivably this process could involve the planning group or a steering group recruited by the planning group to oversee:

   ⊄# an appropriate consultation process;

   ⊄# the drafting of the final principles;

   ⊄# their endorsement and adoption by key stakeholder groups including consumer and research organisations; and

≠# their submission to the councils or boards of key funding bodies for their incorporation into the application funding and reporting process.

Critical target funding bodies include but are not limited to the *National Health and Medical Research Council, the Australian Health Rotary Research Fund* and *Medicines Australia.*

A second priority of the planning group will be to consider ways in which the priorities for action identified in the preworkshop consultation process can be progressed. These priorities include:

≠# Awareness and cultural change

≠# Skills and knowledge

≠# Networking and communication

≠# Funding and resources

≠# Evaluation of participation process/outcomes.

One option that could be considered is for the planning group to establish working groups to develop action plans for each of the priority areas, The resulting action plans could then be compiled by the planning group for further stakeholder consultation and submission to a Second national forum on promoting consumer participation in research at which the plans could be modified, refined and prioritized. The work of the planning group and the working groups will be assisted by *BrolgaNet* (http://brolganet.anu.edu.au), a tool for facilitating communication between stakeholders interested in consumer participation in mental health research.

In conclusion, the time is right for stakeholders to work collectively to develop a model for promoting consumer participation in research that will improve the relevance and quality of mental health research and serve as a best practice model for other fields of health.

Section 1: Background

You've probably heard the story about the drunk man who lost his wallet and was discovered by a passerby searching for it under a light post.

'Are you sure this is where you dropped it?" asked the passerby.

'Oh, no mate', replied the drunk, 'I dropped it in the gutter, but I can see much better over here.'

I suspect that sometimes mental health researchers are a little like this misguided man. However, instead of a wallet, they have misplaced something called 'the right questions' and 'relevant research'. Unlike the drunk man, they do not know they are focusing their search in the wrong area. However, just as the inebriated man would be aided by a torch, the researchers would benefit from the illumination that could be provided by working in partnership with consumers with lived experience of a mental disorder.

From K. Griffiths. *The Australian Health Consumer*, Promoting consumer participation in mental health research in Australia, 2004, Issue 3, p. 11.

Background to the report

There is increasing recognition both internationally and in Australia of the importance of active consumer involvement in mental health research.

This recognition has been reflected in a series of articles and commentaries in high profile medical journals such as the *British Medical Journal*, the *Lancet*, and *The British Journal of Psychiat*ry and also in policy documents and standards both in Australia and overseas.

Increased consumer participation in evaluation is an identified outcome for the 'strengthening quality' priority theme in the current *National Mental Health Plan 2003-2008* and the plan identifies encouraging 'meaningful consumer, family and carer participation at all levels' as a key direction for achieving this outcome (p. 28). Recently, the National Health & Medical Research Council (NHMRC), in conjunction with the Consumers' Health Forum of Australia (CHF) released a *Statement on Consumer and Community Participation in Health and Medical Research* acknowledging the benefit and rights of consumers to participate in health research.

However, the challenge will be to translate these in-principle recommendations into action. A study conducted by ANU's Centre for Mental Health Research (Griffiths et al, 2002) found that consumers and carers placed a significantly higher priority on consumer participation than researchers or other professional stakeholders.

As a first step towards action, ANU's Depression & Anxiety Consumer Research Unit and the Mental Health Council of Australia sought funding from the Health Priorities and Suicide Prevention Branch of the Commonwealth Department of Health and Ageing to convene a national workshop to identify principles, priorities and strategies for promoting consumer participation in mental health research. The Commonwealth agreed to provide major funding for a meeting of stakeholders and a workshop was subsequently convened in Canberra in June, 2004.

This report summarises the activities that were carried out during and in association with the workshop.

The Methodology

There were four main activities associated with the workshop. The first involved a stakeholder survey prior to the workshop. The second comprised a series of background lectures at the meeting. The third took the form of group activities

at the workshop. The final phase involved the integration following the forum of principles developed by the workshop groups.

(a) Pre-workshop consultation

Since only a limited number of stakeholders could feasibly attend the national workshop, a survey was conducted to obtain views from a diverse range of stakeholders throughout Australia (see Appendix D). The survey, which could be completed either online or in hard copy, asked stakeholders to list the advantages, disadvantages and priorities for action for increasing consumer participation in research. It also sought information from respondents about the level and type of consumer participation involved in their past research projects. It was intended that this information would both inform the planning and structure of the workshop and provide background information for the workshop delegates. It was also intended that this systematic identification of barriers *prior* to the workshop, would enable Workshop delegates to focus on developing general *principles* and ways of *overcoming* the barriers and identifying practical methods for *moving forward*. Details of stakeholders who identified themselves and provided feedback as part of this consultation are shown in Appendix E. Other stakeholders provided feedback anonymously.

(b) The Workshop

The *National Workshop for Promoting Consumer Participation in Mental Health Research* was convened by the Consumer Research Unit of the Australian National University (major sponsor) in conjunction with beyondblue: the national depression initiative (sponsor), the National Health & Medical Research Council (sponsor), the Mental Health Council of Australia and the Commonwealth Department of Health & Ageing (major sponsor). A list of members of the organizing committee, planning committee and secretariat for the workshop are presented in Appendix B.

The workshop took the form of a one-day meeting between 32 key stakeholders from around Australia with an interest in developing policy suggestions

designed to promote increased consumer participation in mental health research. Delegates were selected to represent a wide variety of perspectives and included lay consumer researchers; consumer advocates; academic consumer researchers; academic researchers; clinical practitioners/representatives of professional organisations; a journal editor, and representatives from non-government organisations, industry, the media, and Aboriginal and Torres Strait Islander and culturally and linguistically diverse backgrounds. Delegates were primarily mental health stakeholders but some attendees had a broader health background. Biographical summaries of delegates are included in Appendix C.

The meeting was chaired and facilitated by health and media expert Dr Norman Swan of Norman Swan Medical Communications.

The workshop comprised two phases: lectures and group activities.

The lectures

The workshop commenced with a series of six brief lectures by consumer, researcher and policy experts. These lectures were intended to provide background briefing for delegates that could inform their later group activities and decision making. The topics covered included policy perspectives on consumer participation in mental health research (Mr Dermot Casey, Commonwealth Department of Health & Ageing; Ms Suzanne Northcott, NHMRC); an overview of the results of the pre-workshop consultation process (Dr Kathleen Griffiths); and models for consumer participation in mental health and health research (Ms Yolanda Wadsworth; Ms Merinda Epstein; Ms Beth Micklethwaite).

Group activities: The development of Guiding Principles

Two main group activities were planned for the meeting (see Appendix A) including (i) the development of guiding principles for consumer participation in research and (ii) the agreement on priorities for action and short and long term goals for achieving them. However, during the course of the workshop it

emerged that delegates were keen to discuss background concepts, and to explore and explain to each other their differing perspectives. It was considered both necessary and productive that this discussion should take place and thus the background lectures and plenary discussion took longer than had been anticipated. Accordingly, group activities for the day were limited to the development of guiding principles. The development of priorities for action were deferred for consideration by a subcommittee comprising the CEOs of the Mental Health Council of Australia and beyondblue, and the Director of the Depression & Anxiety Consumer Research Unit.

The starting point for the group discussion of guiding principles were two pre-existing sets of principles for consumer participation in medical research. The first involved statements extracted from the NHMRC/CHF *Statement of Consumer Participation in Health & Medical Research* (Appendix F). The second involved principles for successful consumer participation in NHS research and were developed by the University of Sheffield in the United Kingdom (see Appendix G). Each group then reported back to the whole group an aim and a set of principles for consumer participation in mental research and a plenary discussion ensued.

(c) The refinement of the Guiding Principles

The final step in the workshop process involved the integration of the separate sets of principles developed by each group into a single, consistent set of principles. This task was carried out by the first author of this report (KG) at the request of the Workshop delegates and was guided by records of discussions between members of each group.

References:

National Health & Medical Research Council & Consumers' Health Forum of Australia (2002) *Statement on consumer and community participation in health and medical research*. Canberra: Commonwealth of Australia.

Griffiths, K.M, Jorm, AF, Christensen, H, & Medway, J (2002), Research priorities in mental health, Part 2: an evaluation of the current research effort against stakeholders' priorities. *Australian and New Zealand Journal of Psychiatry*, 36, 327-329.

Section 2: The lectures

This section contains edited versions of the presentations by the six speakers at the *National Workshop* on *Promoting Consumer Participation in Research* held in Canberra on 15th June, 2001.

The lectures covered the following topics:

- The Commonwealth's perspective on consumer participation in health research

- The NHMRC's perspective on consumer participation in health research

- Advantages, disadvantages and priorities for action in consumer participation in mental health research: Stakeholders perspectives

The final three lectures presented different models of consumer participation in health research and included:

Consumer directed research : a consumer perspective

Assisting consumers to conduct their own mental health research: The U & I project

Pilot projects for implementing the NHMRC/CHF *Statement on Consumer Participation* in health research

2.1 The Commonwealth's perspective on consumer participation in health research

Dermot Casey
Assistant Secretary, Health Priorities & Suicide Prevention Branch
Commonwealth Department of Health & Ageing

In these opening remarks, Dermot Casey, then head of the Health Priorities and Suicide Prevention Branch talks about the importance of consumer involvement in health research and his hope that mental health might lead the way in developing paths for consumer involvement in health in general. He speaks about the Commonwealth's initiatives for measuring the extent to which consumers have been involved in the evaluation of services and the importance of identifying different viewpoints about what is meant by involvement. He argues for the inclusion of consumer perspectives as a legitimate form of evidence and observes that since the aim is to improve outcomes, consumers 'need to be at the central heart of a research perspective'.

Good morning everyone. Sorry I'm a bit rushed this morning. The difficulty of holding meetings in Canberra is that all of the normal activities must go on, like getting kids out of bed to go to school and all those sorts of things. So I've just made it across town this morning!

I've been asked to welcome you all and introduce this section and I'm doing that noticing that this is the first rain we have had in Canberra for some months. So if you are thinking it is a miserable morning because it is raining we are feeling very happy. We haven't seen this stuff for such a long period of time.

It has also been a pleasure for us to be able to provide some of the resources towards holding this meeting, because I think it is very important that from time to time we sit back and reflect on issues and particularly the crucial issues of the involvement of consumers, carers and the community in the work that we do.

Now, I have been asked to talk a bit about the Commonwealth perspective on consumer participation in research. Well, we don't have one! So I can sit down now… I have been very guarded these days when people ask me to give a Commonwealth perspective, to actually find out whether in fact there is one. I may have a perspective, but given the title of this very short, brief introduction is to talk about the Commonwealth one - in some things we don't and I think that is one of the reasons why we have wanted to facilitate this gathering today, to think about that.

Now clearly NHMRC I think do have a perspective, in that NHMRC, who are going to be speaking shortly, have facilitated the development of the consumer participation statement that is part of your pack and I know that Suzanne will talk a bit more about that. And so in some senses I think that encompasses a lot of the issues that we are going to be talking about today. In my new role, I don't just deal with mental health but with a wide spectrum of National Health priorities and disorders. Therefore I think that what we are talking about in terms of mental health also has and should lead the way in terms of what we think more broadly about the role of the consumer, the customer, or the Community in what health is about, what health research is about, what you want health services about. Whilst we don't have a particular perspective on this topic, not being a research agency, I do think it is fair to say though that the National Mental Health Strategy in its 11 – 12 years of existence has always had as its major focus – consumers – and the purposes for which health social policy is developed is actually to be of benefit to people who are in need, and people who are in receipt of those sort of services. So it goes with out saying that consumers, carers and the community have to be the central focus of anything that we do.

Now we try to give effect to that in number of ways. During that period of time we established the National Standards for Mental Health services in Australia, particularly public specialist mental health services. And a key focal point of standards have been consumers, the role of consumers, respect and appropriate service for their families, a central National about 1995-96,

> *Just because somebody says they involve consumers, it doesn't mean that they really do involve consumers.*

consumers and and that has been tenant of the Standards. Since we have sought to measure and evaluate the extent to which there are formal mechanisms for consumer participation in the planning and running of services in this country. We continue to do that, sometimes with a lot of criticism. Just because somebody says they involve consumers, it doesn't mean that they really do involve consumers. I know that there is very healthy gap about what we measure and what people claim, versus what people experience. That tension is part of a very interesting focal point for understanding what it means for me to say that I involved somebody in something, versus what they perceived as being involved, listened to and their views being taken of account of. So I think that perspective is something that is an issue that can be pursued today. The difference between what I say I'm doing and what you say you're feeling in relation to that activity.

We've introduced into mental health services in this country, both in the public sector and increasingly in the private sector, a belief that we should have outcome measures to evaluate whether in fact the consumer, the person who is receiving those services, has in fact improved their health outcome or their health status as a result of that intervention. It is all well and good people being out there distributing services, but what if they are not any good? What if they actually make no difference? So we've done that and one of the aspects of that was to actually introduce the consumers' perspective, in having their say about what they perceive, what they believe has been the outcome for them. Because in the end they are the ones who are in the best position to evaluate whether in fact their health has improved as a result of those activities.

In doing so, health outcomes measurement has probably been the most difficult area to introduce. We can reasonably get from providers agreement on measures that they would all use. When it came to consumers, and I think this demonstrated the complexity of giving real meaning to the consumers' voice, we were unable to settle on one perspective or one measure that everybody was comfortable with. So what we have done is said well lets use a number of different measures, lets use a number of different perspectives. And lets look at seeing over a period of time, whether we can actually draw a consensus.

So in short, and sort of wrapping up from my very brief notes, the focus for today and the focus for this discussion, and I think the focus for what we are trying to do is to improve the health outcomes for consumers, to improve the situation for carers, the families and the community. And in that sense, our perspective on this is that consumers need to be at the central heart of a research perspective. They need to be there to give effect to the idea that for the consumer the areas in which we research are also very relevant. Trying to draw the into research questions is going to be of importance. I don't think it has happened here but in the UK, they have recognised that the consumer perspective is a legitimate level of evidence. The Hierarchy starts with the randomised control trial and goes all the way down the five levels of evidence to include a sixth, the consumer perspective. I would summarise that as what the "punter" thinks. It is what is the perspective of the people who are in receipt of this intervention. It is in itself a valid form of evidence in evaluating our research and evaluating our activities. I would like to see that come in to Australia, that we do have that level. Of evidence what do people think

> *I think the focus for what we are trying to do is to improve the health outcomes for consumers, to improve the situation for carers, the families and the community. And in that sense, our perspective on this is that consumers need to be at the central heart of a research perspective.*

about what we are doing, what it is we are saying, and what we claim is the effectiveness of the interventions that we are involved in providing?

I am not going to be able to be here all day today. Changing the date of this event got me out of one commitment but it put me into another one. It is the last two weeks of the parliamentary sitting term and so I need to be back in my office by mid morning. But I do hope that this workshop is going to be useful. I think it has been a good investment to bring you all together and see whether we can get much more of a sharper focus into our research, not just in mental health (I know today is the focus of mental health).

Discussion

Norman Swan: Before you go, is that investment over the mental health plans in the consumer focus paying off? You might see more consumers at the table but is it actually changing policy in a tangible way? So far it has been very much a service focus rather than a research focus. In terms of would you have done it any differently, to get more effective consumer involvement in the service side of things?

Dermot Casey: I think in retrospect we might have been more interested in seeing what we could facilitate in terms of more of a bottom up than a top down approach. When this business started it was very much a top down approach to change, so introducing things like National Standards or Consumer Outcomes was about "you will do what we tell you" in terms of the industry and I think it might have been more useful in retrospect if we had done more scattering the seeds and seeing what would grow. Because I think some of the models that we have developed have weaknesses that are associated with the need to have a structural top down approach.

2.2 The National Health & Medical Research Council's perspective on consumer participation in health research

Suzanne Northcott

Executive Head, NHMRC's Centre for Research Management

National Health & Medical Research Council

In this presentation, Suzanne Northcott talks about the NHMRC Statement on Community Participation in Health and Medical Research and its role in the strategic planning of the NHMRC. She notes that there is now consumer representation on each of the four principal NHMRC committees, including the Research Committee. The Research Committee has developed strategies for involving consumers in their work and has appointed an implementation committee to oversee this work. Future research grant applicants will be required to justify their research in terms of their dissemination strategies and plans for consumer involvement in the research and institutions accredited with the NHMRC will in the future be required to comply with the NHMRC's new consumer statement. Finally, she discusses the way in which principles developed in the present workshop might be presented to the NHMRC and incorporated into its work.

Thank you everyone. Once again like Dermot, I have to rush off again at morning tea, not just because of Parliamentary demands, but also because our

offices in Woden were burnt quite severely about 10 days ago. We've now all been relocated and can go on with everything that is on the system, but we have no access to paper files etc. We're in the middle of our peer review process and things are always really hectic at this time of the year, but they are even more so at the moment.

I am going to talk about the NHMRC Consumer Health Forum *Statement on Community Participation in Health and Medical Research* in particular. The stuff that relates particularly to mental health research, for as Norman has said we hope that it will provide some assistance and guidance to the exercise here today.

The NHMRC's Research Committee commissioned production of the *Statement* in 1999 as a result of the recommendations of the Wills Review which took place in 1999 and made a lot of recommendations about how research really needed to involve consumers much more than it ever had in the past. That researchers must think about the relevance and the right of consumers to have an interest in what they are doing, particularly at the basic end of the research spectrum. That's what we have been trying to change. So the NHMRC commissioned the Consumers' Health Forum to undertake extensive consultations with a range of different organisations and individuals. Beth Micklethwaite, from the Forum, is going to talk about the project that has now started and been rolled out of all of this exercise.

The *Statement on Community Participation in Health and Medical Research* was presented to the Research Committee by the Consumers' Health Forum in 2001, and in turn the Research Committee commended it to Council, which endorsed it in October 2001. The *Statement* is now very much a key part of Council's strategic planning for the current triennium.

We now have consumer representatives on all of the four principal committees of the NHMRC, and also on Council. And implementation of the *Statement* is required as part of the Council's Strategic Plan. Our four principal committees are:

- the Licensing Committee which is responsible for stem cell legislation and Human Cloning Act;

- the Australian Health Ethics Committee;

- the Health Advisory Committee;

- and the Research Committee.

And while some of the other principal committees have had consumer representatives on them, for the first time ever the Research Committee now has a consumer representative on it, and that is Mr Clive Deverell from Western Australia. I would like to take the opportunity to say what a fantastic contribution Clive has made to that committee and it keeps him very, very busy.

There are basically six strategies in the current triennium that Research Committee is pursuing to ensure consumer involvement in all of its research activities and working committees. We have an implementation group which has three members from the Research Committee: Clive Deverell and Bruce Robinson, both from WA, and Sandra Eades who is one of the two Indigenous members of the committee. (That is another recent achievement of the NHMRC: Each of our principal committees have two Indigenous representatives as well).

The six strategies are:

- Expanding consumer representation on Research Committee working groups

- Commending the *Statement*

- Providing information to consumers about the role of Research Committee and developing a network for information and support

- Ensuring researchers support the rights of research participants to the results of the research and have access to their own results

⧧ Ensuring participation is part of good research practice

Monitoring implementation

In addition to representation on each principal committee, the Research Committee has now involved a number of consumers on some of its major working committees, and also through some of the peer review processes that we run. And that's becoming a more extensive practice. At the moment we have lay or consumer

> *The Statement is now very much a key part of Council's strategic planning for the current triennium.*

representatives who sit on the Population Health Capacity Building Peer Review Panel, HealthCare, the palliative care program that we run in partnership with DHA and our Enabling Grant Peer Review Panel.

The second strategy is commending the *Statement* which is basically getting out there and publicizing it. As of 2005 all research applications that come to the NHMRC, not just project grants, will have to describe to the peer review panel how they're going to promulgate their work, and how they are going to involve consumers in the course of the research project.

Discussion

Norman Swan: And that of course will include mental health researchers applying for NHMRC grants.

Suzanne Northcott: Anyone. And it will include people who are doing basic bench research which can be seen as quite confronting for some of these researchers, but such research does have an impact ultimately on the health of the Australian population and we want people across the research spectrum to really think about what is the significance of their research in terms of the Australian community? And what we will also require as of 2005 is that at the end of each research project that you do, you will have to submit a final report. You will have to talk about what you achieved through the research. That final

report will have to include information on consumer and community involvement and how they promulgated that.

Norman Swan: That's quite an important point actually because, what ever we come up with here. If it imposes an entirely different set of rules and regulations or whatever, on researchers, you'll be doubling up. Because of having to conform to NHMRC guidelines/statement anyway.

Suzanne Northcott: Not necessarily because as with Indigenous health, which I'll get to, there will be specific criterion that researchers need to address from the outset and will also have to address at the end of their research. I think the two are complementary, I don't think it has to be doubling up. If you came up with a set of principles out of this process, or somewhere further down the track, that you want the NHMRC to consider, it would have to go through the process of going to the Research Committee and being signed off by Council, but I don't think it has to be a duplication by any means.

So just a bit more on the second strategy. All new applications for NHMRC Accredited Research Institute status must comply with our new Consumer Statement. Accredited Research Institutes are the organisations that take on the responsibility for administering NHMRC funds. At the moment when they sign up to accept a grant on the behalf of one of their researchers they agree to ensure compliance with the National Statement on Ethical Conduct in Research Involving Humans and other such guidelines.

All new applications for NHMRC Accredited Research Institute status must comply with our new Consumer Statement

And now they sign up to will have to agree that all research conducted will be done in accordance with the Consumer Statement.

The third strategy is providing information to consumers about the role of Research Committee and developing a network for information and support. We are currently redeveloping our website, and Clive Deverell is involved in that activity, specifically to try and ensure that our website is accessible to consumers, so that they can find information more easily. The names and contact details of

our consumer representatives will also be on the website so that people can get in touch with them.

Very importantly, the Statement requires the researcher to provide access to the results of research to consumers who have been a subject. That is consistent with the NHMRC's National Statement on Ethical Conduct in Research Involving Humans. We are also

> *We really want students and young researchers to understand the importance and value of involving the community and consumers in research design.*

very keen to ensure that participation of consumers just becomes a normal part of the research process, in the same way that good ethical practice is. If junior researchers are taught appropriately about good ethical practice, it shouldn't be too difficult to get a proposal through an ethics committee. Ditto we really want students and young researchers to understand the importance and value of involving the community and consumers in research design.

OK, monitoring and implementation. We are not just talking about this, we've actually introduced business planning with Research Committees. We've always had an overarching Strategic Plan for the Council but it has never been rolled down to the Committee level - we now have an Evaluation and Outcomes Working Committee reporting to Research Committee. This committee includes a consumer representative and is responsible, among other things, for monitoring and reporting on implementation of the Statement to the Research Committee.

We have gone a very long way in terms of ensuring that Indigenous health research does involve meaningful consultation with consumers. A committee that's largely made up of active Indigenous health researchers has been established and every project grant or program grant application we received is assessed by this panel before it goes through the normal peer review process. In the first instance the panel goes through and makes sure that every research proposal where applicants have ticked the box to say 'yes this is an Indigenous health research proposal' the proposal actually meets these criteria: there must be

consultation with the community; the proposal must be of benefit to the Indigenous population at large; and it must be sustainable and transferable beyond the intervention. So it can't just be about solving otitis media in remote communities by bringing in lots of GP's and asking them to stay there at the end of the intervention. It really has to be something that is sustainable post research. It has to be transferable between Indigenous communities; it has to build capacity, not just in terms of Indigenous health researchers but in terms of Indigenous communities and their ability to actively participate in research. And basically it has to have priority and significance, it has to be important to the community, it can't be a very interesting but very esoteric research question that is not actually going to contribute to raising the standard of Indigenous health.

The NHMRC has also been looking at how international research organisations involve consumers. The Juvenile Diabetes Research Foundation (JDRF) is a US organisation with which we have a number of really interesting research collaborations. We've really learnt from them about how they have, since the mid 70's, involved lay people, usually the parents of kids with type 1 diabetes, on their panels. We are currently in the process of codifying what is the appropriate role of consumers on peer review panels. We think that they have a very valuable role to play, but that they shouldn't be intimidated by having to assess the science of a particular proposal. Consumers do however play a significant role in talking about the relevance and the importance of a particular intervention.

So we've done a lot but it's only really the beginning in terms of reaping the rewards and we recognise consumer involvement is an evolving process. We really hope that in the next five years consumers across the board will be much more actively involved in research funded by the NHMRC and as a result the research will be much more consumer relevant.

Discusssion

Norman Swan: Thanks Suzanne, I just want to talk about this implication and come back to it because it will be a key issue in the room and I want to clear it up

for my own benefit… ... So mental health researchers who want to apply for NHMRC funding are really going to have to sign up to this scheme? And that would be most mental health researchers in the country, so in a sense this does frame the game?

Suzanne Northcott: It does but in a very macro sense.

Norman Swan: But what I was talking about was duplication. If we came up with something that is very different from this, there would have to be a loop through the NHMRC.

Suzanne Northcott: For our funding, for anything that we fund, there would need to be a negotiation process between NHMRC and whoever the organisation would be. But I think that door would be open…

Norman Swan: I'm sure, so the risk that we need to avoid is having two parallel processes, which would double up on the work?

Suzanne Northcott: Yes

Norman Swan: We really want to integrate it into one.

Suzanne Northcott: And you want it to be meaningful: we require institutions to sign off that they comply with the Statement, and applicants will have to address the Statement in both terms of the project proposal and the final report. But I expect that there is a reasonable chance for some degree of lip service to be paid to the Statement. That's why, in the area of Indigenous health, very specific criteria and an additional process have been developed.

Norman Swan: So this might well be appropriate in mental health research too?

Suzanne Northcott: Possibly. The resources available to the NHMRC in terms of monitoring these things, to be honest, are limited. We can do it when we receive a proposal because we have a very resource intensive front end in terms of assessing all our project grant applications.

2.3 Advantages, disadvantages and priorities for action in consumer participation in mental health research: Results of the pre-workshop consultation survey

Kathleen M Griffiths & Affrica Jenkins

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Centre for Mental Health Research, The Australian National University

A number of writers and others have discussed the perceived advantages and disadvantages of consumer participation in health research and the processes by which consumer participation might be promoted. However, to date there have been no systematic reviews of stakeholder views on these topics. In this presentation, Kathy Griffiths describes the results of a national consultation survey designed to obtain feedback about consumer participation in mental health research with the aim of providing (a) a framework for the workshop planning processes and (b) input that would inform the decision making of delegates to the meeting. In this talk she summarises the themes that emerged from feedback provided by over 170 respondents to the consultation.

One of the difficulties of holding a workshop such as this is that only a limited number of delegates can attend. In order to ensure broader stakeholder input into the workshop process, we sent out a pre-workshop consultation survey to

over 1500 individual organisations and individuals. The input we received has been used to identify the proposed priorities for action to be considered today and I hope it will also inform today's deliberations and discussions.

The Survey

The stakeholder survey (see Appendix D) was sent out by e-mail and/or hard copy to

- all member organisations of the Mental Health Council of Australia;

- university academics in Psychology and mental health related departments and research centres around Australia;

- all Divisions of General Practice;

- professional Colleges,

- members of the National Mental Health Working Group;

- pharmaceutical companies

- relevant government departments; and

- mental health services and service organisations (private and public)

Survey recipients were asked to forward the questionnaires to other stakeholders with a potential interest in responding. Five hundred additional hard copy questionnaires were sent to VMIAC at their request for this purpose.   Recipients could complete the questionnaire in hard copy or online.

The survey asked respondents to identify:

- three advantages of active consumer participation in mental health research

∉# three disadvantages

∉# three priorities for action to promote consumer participation.

It also sought information about the stakeholder background of the respondent and to specify the highest level of consumer involvement in research in which they had participated.

Survey results

Characteristics of respondents

Figure 1 shows the percentage of people from different stakeholder backgrounds who filled out the questionnaire. People could be more than one type of stakeholder at once so although the numbers are percentages, they do not add up to 100. Of the people who filled out the survey almost half were consumers, just over one-third were health care professionals, 27% were mental health researchers and a quarter were academics.

Level of involvement in research.

Of the 184 people who had responded to the questionnaire at the time of the analysis, 59% stated that they had been involved in mental health research as a researcher and/or a consumer.

We asked respondents who had participated in mental health research to rate the extent to which consumers were involved as active participants in the project with most consumer involvement. Ratings were from 1 (passive participant) to 7 (project leader).

Figure 1

Stakeholder representation
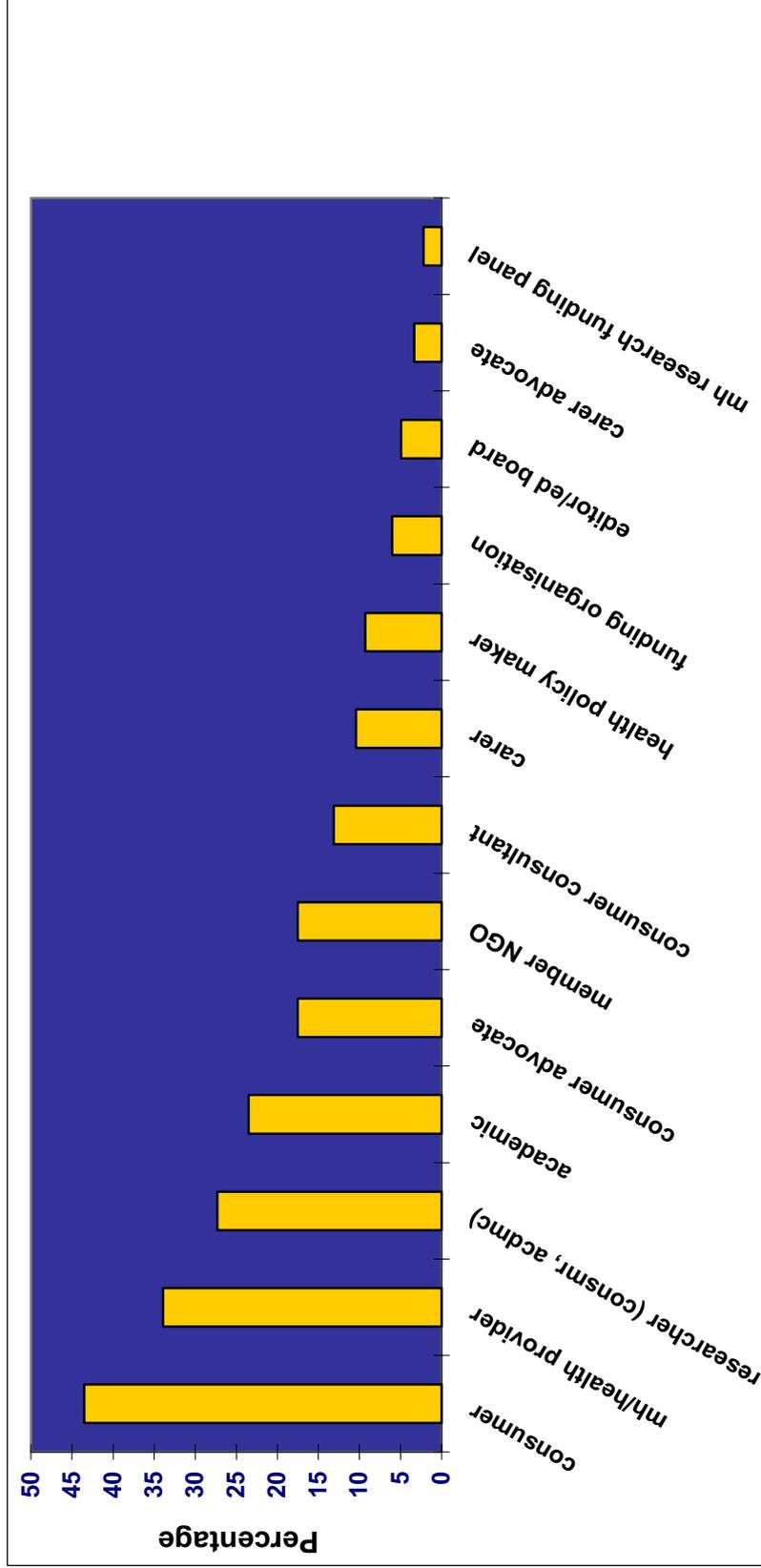
The results are shown in Figure 2. As you can see, a significant percentage of repondents with research experience had been involved in projects where consumers were not passive participants. Indeed, eighteen percent had been involved in research in which a consumer was the project leader and about half in projects where consumers played a relatively active role.

Figure 2
Level of consumer participation
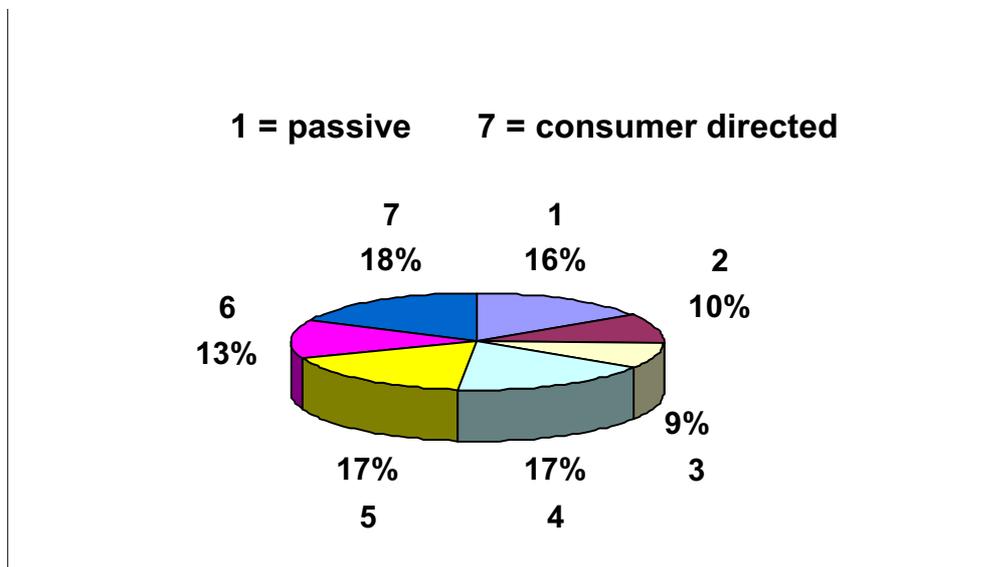
Advantages of consumer participation

Overall, advantages of consumer participation fell into three broad categories: advantage to the research project; advantage to public health and advantage to the consumer.

Figure 3
Advantages of consumer participation in research

Advantages of consumer participation in research

Research Project
a. expertise
b. broader/different perspective
c. more relevant research
d. facilitate resrch & dissemination process
e. more ethical research
f. increased researcher accountability
g. consumers value/promote research

Public Health
a. improved mh services
b. improved health outcomes

Consumer
Empowerment
a. acknowledgment of expertise
b. ownership
c. voice
d. contributing to society
e. destigmatisation

1. Research project

Looking first at the research project advantages, several themes emerged as to why consumer participation was advantageous. These included (a) contribution of consumer expertise; (b) providing a broader/different perspective; (c) promoting more relevant research; (d) facilitating research & dissemination process; (e) more ethical research; (f) increased researcher accountability; and (g valuing and promoting research in the broader community.

Let me briefly summarise each of these in turn.

(a) Valuable experience

The most commonly cited advantage of active consumer participation in research was that consumers, by virtue of their 'lived experience' are mental health experts who can make significant contributions to the research project:

> *They may not know the science but they know how it feels. They can express feelings. Their input can direct research where it is needed, rather than where researchers may want it.'*

> *No one understands better about mental ill health than consumers. Their experiences are unique.*

(b) Broader/different perspective

A closely related, and commonly cited advantage of consumer participation was that consumers can bring a different perspective to mental health research. For example, one respondent noted:

> *Valuable insights can arise from consumer perspectives, and these can be blended with service provider knowledge in various ways. New synthesis forms of knowledge, understanding and communication become possible.*

and another said:

It gives a very important perspective to the research – to the development of the hypothesis, understanding of the issues, importance and relevance of the research to consumers.

(c) More relevant and valid research

Many respondents expressed the opinion that active consumer participation would result in more relevant and valid results:

Creating research that is in keeping with the real needs of consumers not their perceived needs.

*Having consumers input enables all stages of the research process to be as **appropriate to on the ground outcomes** as possible.*

And similarly:

[Consumers are] better qualified to ensure that research also sheds light on the practicability and sustainability of treatment regimes under normal conditions of doctor patient communication or lack of it, and the exigencies of everyday life.

Linked to the issue of relevance was the observation that consumer participation would enable consumer input into research priorities and questions:

Consumer participation means that issues that are of most consequence in the lives of those who suffer from mental health problems are addressed with most priority.

(d) Facilitation of the research and dissemination process

With respect to implementation of research, it was argued that consumers could facilitate the recruitment, engagement and retention in the project of their peers and promote more insightful interpretation of the data and better dissemination.

Consumers on research teams will mean that different data will be collected as consumer interviewers or focus group convenors will be told [about consumer information] in ways that are unavailable to professional researchers and practitioners.

Consumers may by virtue of their participation encourage a greater diversity of research methods for collecting information, and may *'be able to provide advice regarding research design, for example how the conduct of the research will impact on and be perceived by research participants'* and *'how to get the best information from clients'* It was also felt that consumers could provide insights into the interpretation of data by, as one respondent put it, *'adding the phenomenological interpretation of the data to the raw numbers.'* One participant noted that consumers:

> *… can also be helpful in analysing results, especially in social research as the themes and questions they may interrogate the data with can add another dimension to the work.*

> *Input into the phrasing and composition of surveys (for example) can greatly assist the uptake of these, and the ability of consumers to complete them with meaningful data and information.*

Consumers often do not find out about research findings. However, a small number of people noted that consumers could facilitate communication of research findings:

> *For example, findings published in a scientific journal may not be accessed by many consumers, but reporting findings in a consumer friendly manner, such as through newsletters and virtual networks, ensures that the results are received at a 'grassroots level.*

(e) A more ethical and consumer sensitive approach

The participation of consumers in research was thought by some people to lead to a more consumer sensitive and non-patronising research approach:

> *This will help to ensure that research is informed by humanitarian concerns and is executed with sensitivity.*

> *Consumers on research teams will be sensitive to the issues of dignity, confidentiality, privacy and respect in very special ways that may not be obvious to researches who have not had consumer experience.*

Some participants also mentioned the importance of consumer participation with respect to adopting an ethical approach to research and protecting the consumer from inappropriate and/or harmful research:

> It…provides a direct 'feedback loop' and may help to protect consumers from personally invasive research or misguided 'welfare'.

> Reduces the likelihood of exploitive research.

(f) Increased researcher accountability

It was noted that consumer collaboration enables researchers to receive feedback about their research and it also introduces improved transparency and researcher accountability, *'particularly with respect to 'the researched' and to the community'*.

> Ensures accountability of researchers to 'the researched'.

> Energise researchers and hold them accountable…Research should have an orientation of accountability and 'service' to the community.

(g) Increased value of research by consumers

Finally, a number of participants thought that consumer participation may enhance the value consumers place on research.

> Better informed consumers have greater understanding of the value of research.

2. Public Health advantages

The second advantage of consumer participation that emerged from the consultation input were public health advantages both in terms of improved services and improved outcomes.

(a) Improved services

A number of respondents indicated that consumer participation in research would result in improved mental health services and more consumer focused services:

> *Service delivery can be altered and improved upon as an outcome.*

> *Mental health system that is more responsive to the needs of people who access the system.*

(b) Improved health outcomes

Some participants also indicated that consumer participation would improve health outcomes:

> *Consumers are better placed to indicate areas for research that will have an impact on the achievement of better health outcomes*

> *Active consumer participation leads to improvements in health outcomes.*

3. Advantages to the consumer

The third identified advantage of consumer participation in research was consumer empowerment through (a) the acknowledgement of consumer expertise; (b) providing consumers with a sense of ownership; (c) providing consumers with a voice; (d) providing an opportunity to contribute to society; and (e) destigmatisation of mental illness.

(a) Acknowledgement of consumer expertise

As one respondent noted, participation in research:

> *Empowers mental health consumers by not treating them as victims or passive recipients, shows respect for the knowledge and skills they possess.*

(b) Providing consumers with a sense of ownership

It was also felt that research participation provided consumers with a sense of ownership with attendant greater sense of control:

> *Their active participation may promote greater 'direct ownership' of research outcomes that are frequently being directed at them. This may result in a greater sense of control over their own mental health and a greater sense of being able to help themselves.*

(c) Providing consumers with a voice

Participation provides consumers with a voice:

> *That people without a voice now have one. It means that we can give up to date information on what is happening, the issues, concerns, treatment, stigmas and anything else that directly effects consumers can be addressed.*

(d) Opportunity to contribute

It also provides the opportunity to contribute in a way that benefits others and themselves and enhancing their sense of control and self-esteem.

> *Creates opportunities for consumers to use what they know to make a positive contribution to the mental health system- this can lead to real changes in consumers lives, a feeling of usefulness, empowerment, social connectedness and more.*

(e) Destigmatisation

Consumer-researcher partnerships also have the potential to empower consumers by destigmatising mental illness:

> *Helps overcome stigma and empowers consumers by treating them as partners in the research.*

Disadvantages of consumer participation.

Disadvantages included those which were a threat to the integrity of the research project, those which would impact on the consumer and those with impact on the researcher (see Figure 4).

1. Threat to project

Four types of threat to the project were mentioned by participants. These were illness, lack of knowledge by consumers and researchers, lack of representativeness among consumers and increased cost resulting from consumer participation (see figure 4).

(a) Illness

The first major disadvantage is related to the impact of consumer illness on the research. There were three areas of concern: lack of objectivity, project delays, and lack of competence.

Lack of objectivity was the most frequently cited disadvantage of consumer research:

> *Excessive bias resulting from personal experience – assuming everyone's experience is similar to one's own.*

> *Lack of objectivity and identification with the research subjects and hypothesis has a potential to interfere with the choice of hypothesis and rigour of methodology and possibly the objectivity of the reporting and discussion at the write up stage.*

But also:

> *Many of us have a particular 'axe to grind' … not an all round viewpoint.*

> *May be difficult for some consumers, especially when unwell, to continue to see the big picture (or is this just me??:0)*

Figure 4

Disadvantages of consumer participation
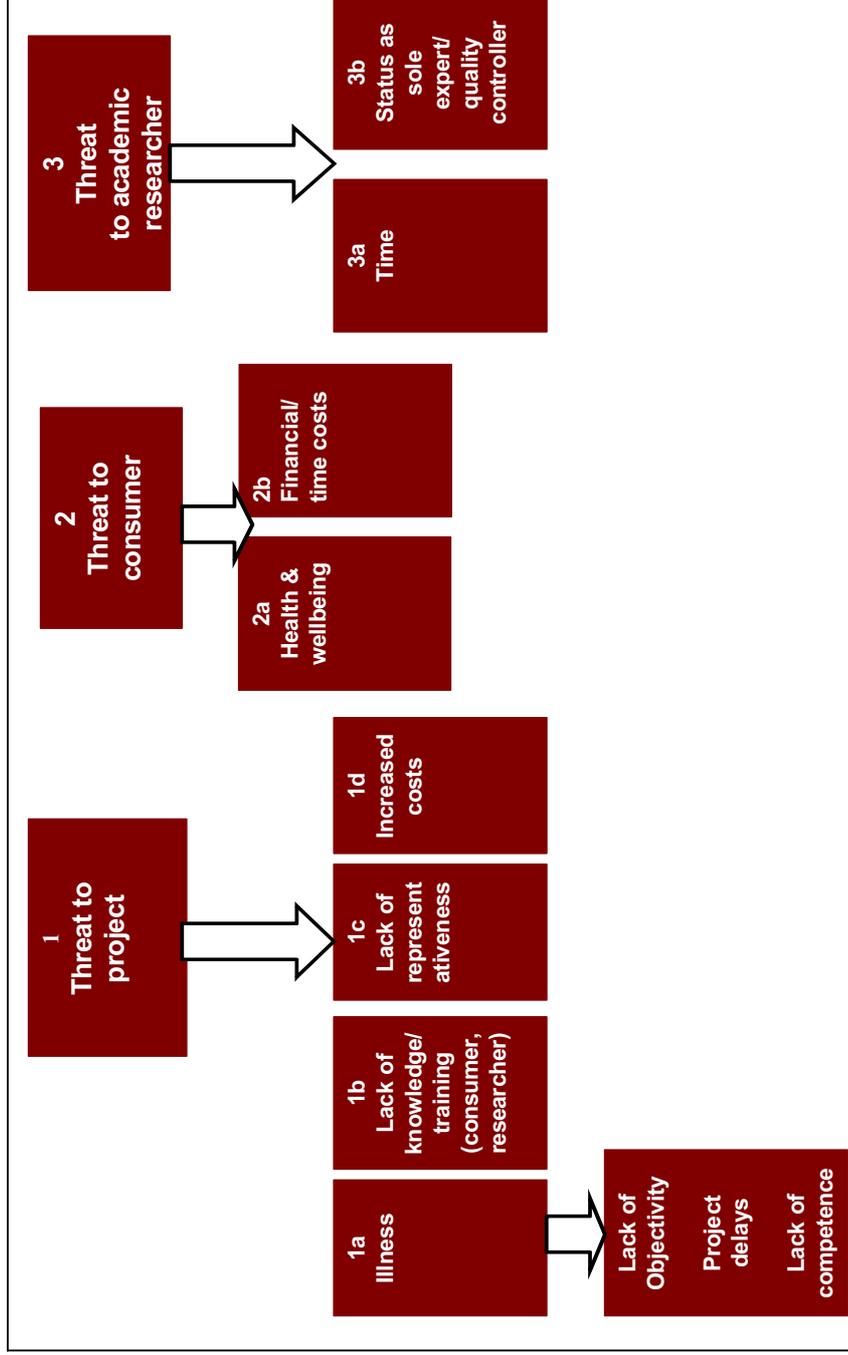
The second commonly cited disadvantage connected to the illness was that if a consumer becomes unwell, this might delay or stop the progress of the project.

Rather than a disadvantage, I would say a difficulty – is that consumers can and do become unwell with a resultant delay in program deadlines being met.

Accommodations for changes in participating consumers' mental health needs...are likely to be needed. Likely to be perceived as yet another hurdle that slows, and hinders research by some researchers.

A final, albeit infrequently mentioned disadvantage relating to illness, concerned 'competence' or more specifically 'lack of competence' to participate. In this respect the 'influence of the symptoms themselves' was mentioned. For example, one consumer/carer noted:

Clients who are unwell (or psychotic) cannot lodge an intelligent vote on certain things. If you CANNOT lodge an intelligent vote you should NOT be able to determine, through voting, certain outcomes.

(b) Lack of knowledge

The second most commonly cited category of disadvantage of consumer participation related to lack of knowledge and training among consumers. This included lack of knowledge of the subject matter, of research, of methodology, jargon, ethics, how to interpret results and policy.

Much research can be overwhelming to the 'average' consumer as it is fraught with jargon and strategies outside the realms of experience – this can create the great divide between consumers and researchers.

A small number of people suggested that researchers may compromise the research project by not understanding how to effectively incorporate consumer contributions into the project.

(c) Lack of representativeness

Lack of representativeness was another concern of some respondents, particularly where consumers were represented by individuals without a framework from which to consult more broadly.

> *Consumer representativeness is always in question: who and how many are represented by each consumer if they are present in an individual rather than an organisational capacity.*

> *The disadvantage arises when there is not a framework from which to draw a representative view rather than an individual agenda.*

Another person noted:

> *You cannot include everyone with a particular problem or their carers, or even a sizeable portion … how do you decide who to include? Is equity of consideration and inclusion necessary? I think it is an extremely difficult area to find a satisfactory solution to. And I do not think that we can necessarily assume that carer groups or advocacy groups are always representative of the widespread interest of individuals with mental health problems, their carers and families as a whole. Keeping the participation restricted to that level does not seem to me to necessarily ensure 'better' consumer participation.*

(d) Increased costs

The final theme relating to threat to the research project was increased costs. In particular, it was felt that it was difficult to gain adequate funding for resources to support consumer participation including research, training and support infrastructure as well as payments and reimbursement of consumers. As one participant noted, *'it takes time and money to support consumer participation properly.'*

2. Threat to Consumer

Respondents also mentioned threats to the consumer. These included potential consumer distress, and financial and time costs to the consumer (Figure 4).

(a) Health and wellbeing

With respect to consumer distress, the most commonly cited disadvantage related to the pressure and overload that might be created by participation in the research process

For example, it was felt there may be a tendency to:

> *'overuse' expertise of certain consumers which could be detrimental to their wellbeing.*

Other respondents noted:

> *The potential stress and anxiety caused by involvement, and the possibility of this exacerbating illness and disability.*

> *At times, because consumers can be unwell at the time or feel stresses by the process, this needs to be handled sensitively.*

Another respondent noted that research:

> *can make consumers anxious – often requires a great deal of patience, rapport building and empathy and understanding on the part of the researcher to avoid too much anxiety occurring.*

This was considered by some as a particular risk if the consumer did not receive appropriate support.

Negative researcher views, particularly, tokenism and lack of respect were linked to adverse consumer outcomes by many people:

> *If the involvement is not properly handled and integrated it feels patronizing and 'tokenistic', which is worse than not involving consumers at all.*

There are disadvantages which stem from the attitudes of some of the people they may be working with on the project, eg. clinical staff, doctors etc, may not be respectful of the consumer, not valuing the experience their lived experience can bring.

Stigma and stereotyping was also seen as a potential problem by some as described by a further respondent:

Another important barrier is that once you become a participant you could be seen as a walking mental illness and not a person who has various other roles in life such as an employee, student, social worker etc. There is always a risk in participating in MHS because of the myths and stigma associated with mental illness

Finally, it was noted that focusing on illness could distress consumers.

(a) Financial & time costs

A major and recurring theme among responses related to the issue of pay for consumers. Certainly, lack of recompense for time, and expenses was seen as a problem:

We need to have support to do this work as it drains our already limited funds due to a lot of us being on the Disability pension.

Most live on or below the poverty line which impacts on their ability to participate.

Need to value consumers input by payment of some kind that will not decrease their pensions – they need to be given not only recognition but adequate payment.

Respondents also noted that participation could be time consuming for consumers.

3. Threats to the researcher

Threats to the researcher were less frequently articulated.

(a) Time requirement

The main perceived disadvantage to researchers of consumer involvement related to the time it was felt that would be required to communicate with and support consumers given their lack of training and potential vulnerability.

> *It is time consuming to consult people who may not understand research.*

> *Slow the process by insisting on attending to issues that the 'experts' (scientists) might want to disregard.*

> *Care needs to be taken when working with consumers due to varying degrees of emotional vulnerability.*

and another comment about time:

> *It may make the logistics of carrying out a research project much more cumbersome and may significantly extend the time to carry it out because of competing stakeholder interests and opinions that need to be properly considered, evaluated and integrated.*

(b) Threat to researcher as expert

There was also some suggestion that consumer participation may cause researchers some difficulty in that they no longer had exclusive control or ownership of or status as sole expert on the project. One respondent argued that researchers *have 'a feeling of ownership regarding the intellectual quality'* of their research and noted that *'there would be some anxiety in some types of research should that quality be diluted'* while another stated:

> *I don't see any disadvantages other than the fact that the researcher has to give up his/her role as 'expert' and for some this would be challenging and unacceptable.*

No disadvantages to consumer participation

It was notable that many respondents stressed that there were no disadvantages of consumer participation. For example, one respondent noted:

There are no disadvantages. The more consumer participation the better.

Whilst another wrote:

There are none that I can identify. I have worked in research settings for ... 8 years in several universities and as a contractor. I have always tried to involve consumers and have advocated this. I have a 20 year career in mental health and see no disadvantages in ever involving consumers in any activity.

Priorities for action

Now I'd like to move on to priorities for action. Four main priorities: emerged. These were **awareness**, **skills and knowledge**, **networking** and **funding and resources**, but **evaluation** and **policy** were mentioned by one or two people (see figure 5).

1. Awareness and cultural change

The first priority I'd like to discuss is what I have termed awareness and culture change.

(a) Awareness of benefits

A number of people suggested that it was important to promote the benefits of consumer participation, to provide information about participation and opportunities for participation and one person stressed the importance of disseminating the NHMRC statement of participation. Target groups mentioned for awareness raising included consumers, researchers, the general public, and doctors/providers/services.

Figure 5

Priorities for Action
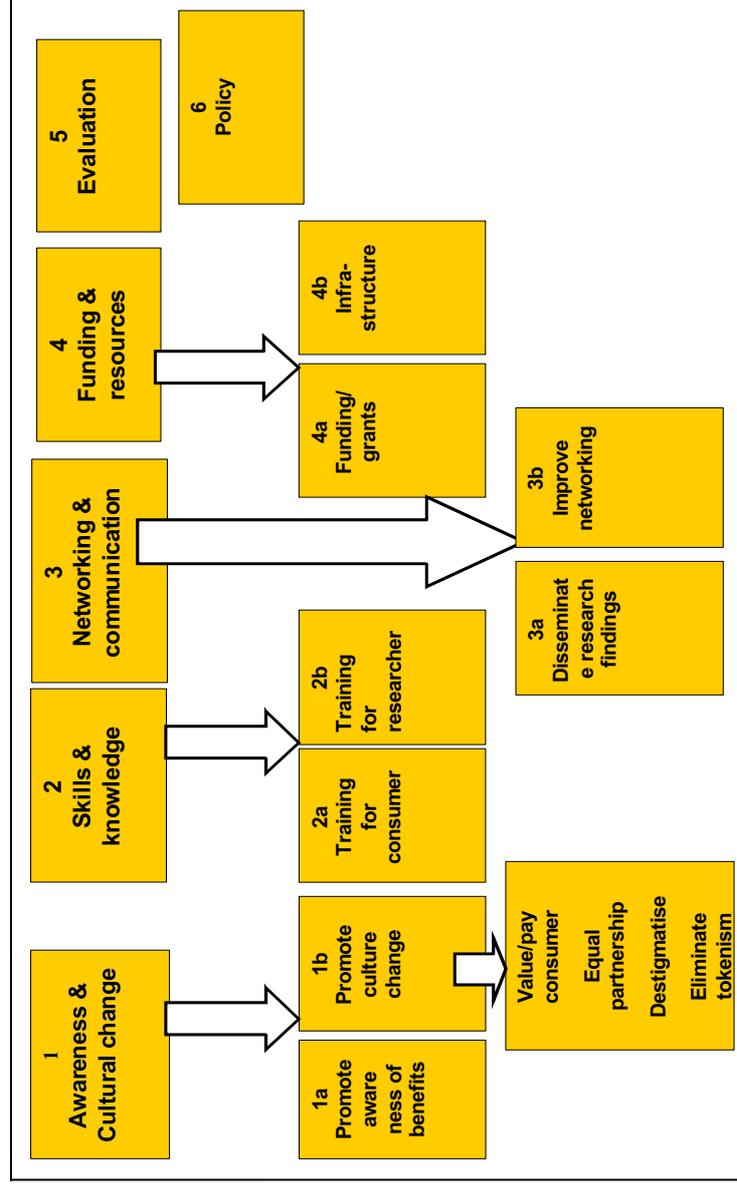
Marketing the need to both consumers and researchers of the desirability to include consumers in research design and implementation.

Increase awareness of mental health researchers of the need and value of consumer participation.

(b) Cultural change

With respect to fostering culture change, the most commonly cited priority was *to pay/reimburse* consumers or otherwise value consumers for their work.

Expecting consumers to freely give their time (and often be out of pocket for transport/parking etc.) for 'the cause' undervalues them and is exploitative.

Consumers must be valued and paid for their time. Other members of the project team – academics, health professionals, policy makers and industry professionals – are all paid.

Other priorities related to culture change included the importance of establishing mutually respectful relationships, eliminating discrimination and stigma, avoiding tokenism, *'provide a sense of research ownership for the consumer'*, acknowledging consumers as experts with equal status, avoiding jargon, creating flexible (consumer friendly) working conditions, and acting on results. The role of management in promoting change was also noted.

In addition pay for work, respondents called for **equality**:

Fostering a culture that accepts consumers' perspectives as having an equal status in discussion.

Develop meaningful, non stigmatic and egalitarian models of participation.

They also noted the need to address the **negative attitudes** of some mental health professionals to consumer participation:

Addressing the negative attitudes of (chiefly) psychiatrists towards consumers as having 'careers' as (mentally ill) consumer consultants. I have also

experienced inappropriate attitudes by psychologists. I find these negative
stereotypes by those in medical leadership positions in mental health research
to be very dysfunctional and dispiriting.

Finally, many respondents emphasised the importance of eliminating **tokenism**.

If you want participation don't just go through the motions. You cannot pay lip
service to participation. It has to be real.

2. Skills and knowledge

The most frequently cited priority for action related to providing consumers with training and education. Topics/areas specified primarily included specific research skills and techniques (eg, research techniques in general, funding sources/processes, interpreting literature, designing and conducting research, interpreting data, evaluating research and its limitations, jargon/acronyms and IT skills). However, more general skills were also mentioned including self advocacy and change strategies, *'public speaking, chairing meetings, teamwork, listening skills'* and policy.

The need to educate and train researchers was also mentioned, but much less frequently.

3. Networking and communication

(a) Disseminate research findings

One theme that emerged was the need to improve consumer access to research findings in general and to the results of individual projects in which consumers were 'subjects', specifically. Methods by which this could be achieved included presentation by researchers to consumers of results, specialized sessions tailored to consumers at conferences and media publicity for research projects and *'ensuring that professionals/practitioners are aware of research and they relay this information on to their clients'*.

More information in the media – newspapers, informal newsletters, discussion on radio, speakers on all forms of mental health issues.

Outreach through groups existing...Radio workshops broadcast on radio Australia etc...Websites, sponsorship of festival or mental health week etc...

(b) Networking between stakeholders

A number of respondents emphasised the importance of networking as a way of promoting consumer participation:

Improved networking/communication between researchers/academic institutions, providers and consumers.

One participant also called for:

a system where consumer ideas for projects can be collated.

4. Funding & resources

(a) Funding

Perhaps not surprisingly, funding was a frequently cited priority for action. It was suggested that funding should be committed to, or a special grants program developed to enable consumers to participate in research. Many made general calls for funding but there were also some specific suggestions:

A funding body (NHMRC, ARC or ARHRF) to allocate some funds specifically to encourage consumer-oriented research projects. Also, try to get a philanthropic body (eg, Myer Foundation) interested to giving a push in this area.

Research funds for NGOs for consumer research was seen as a way of producing a culture shift:

Ensure research funds are made accessible to NGOs (including in partnerships with other NGOs, and not requiring partnerships necessarily with universities). That is, must foster industry-based NGO =research as part of a culture shift.

Grants program for mental health research by/for/with consumers (like the old general consumer research grants program the Consumer Health Forum conducted in the 1980's-1990s).

And one respondent wanted consumer participation to be a condition for funding mental health research:

Ensure consumer participation is included as a funding condition for mental health research.

(b) Support/infrastructure

Suggestions were made that there should be more consumer research positions and more consumer academics and that a Centre for Excellence should be established for consumer research.

Support and 'adequate resources' were also mentioned as priorities, including the provision of technical and IT support and advice and 'outreach - home-based support'.

Finally, there was a call for the development of:

research methodologies that will enable those who are in some way disabled by their mental health symptoms to be able to fully participate.

5. Evaluation

One respondent called for *'consumer evaluation of projects of research before and after they operate.'* There are other aspects of evaluation that are important in my opinion. If we are to promote the benefit of consumer participation in research it is important to develop a range of measures for examining if there are benefits and what they are. This will involve identifying what outcomes are important and how to measure them. There is some work being done by the University of Sheffield in this area.

6. Policy

Finally, policy statements or standards were mentioned as one possible means for moving forward, including from professional bodies and governments:

Policy statements by professional bodies 'supporting consumer participation... (eg. ASPR, APSS, RANZCP)

Set up consumer participation standards across all national and state government and non-government MHS. Involving the consumer in developing the participation. Standards at the beginning and not half way through the process. Consumers must be supported to do this and government must have a political will and fortitude to work with consumers for this to happen across Australia.

I apologise for presenting so much information in such a short period of time. However, I felt that it was important that consumers and other stakeholders not at this meeting today were provided with a voice in this policy process. I am mindful of the time and expertise of the respondents who provided us with feedback in the national survey and I hope that all of us will be mindful of this information as we all consider ways of progressing the consumer participation agenda now and in the future.

Acknowledgment: We would like to acknowledge the contribution to this paper of the many stakeholders who responded to pre-workshop consultation survey (see participant list, Appendix E)

2.4   Consumer directed mental health research: I

Merinda Epstein

Policy Officer,

Victorian Mental Health Legal Centre

There are many models of consumer participation in research. In this presentation, Merinda Epstein challenges the common assumption that the consumer perspective in research is merely about consumers participating as an adjunct to the academic researcher's agenda. She points out that much is known internationally about consumer driven research and emphasizes the importance of rethinking models of research funding and the research process and concepts of expertise. She uses her experiences in a recent research project to illustrate the importance of all researchers understanding the ethical issues involved in conducting research including the potential for research to lead to lowered self-esteem in participants and the need for consumers to educate non-consumer researchers about how to carry out research involving consumers. She further emphasizes the need to involve consumers in the research process from the outset; and the importance of ensuring that all consumers contributing to a project are provided with feedback in an ethical fashion.

Consumer perspective research is not just about adding a pinch of consumer to unchanged and unchallenged research assumptions, and stirring like mad. That cake will flop.

Figure 6
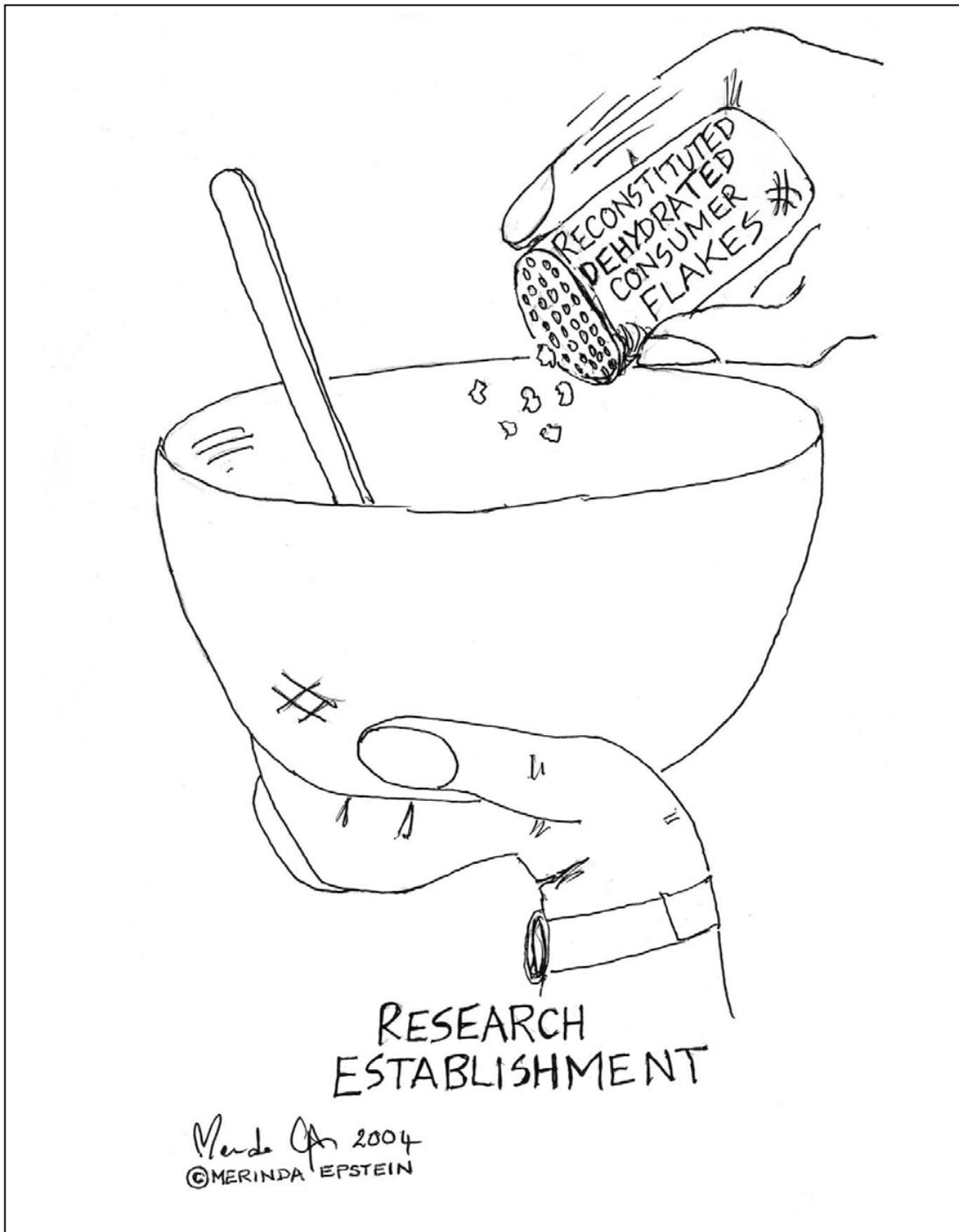
Consumer perspective participatory research challenges us. It's meant to. It challenges the way that research funds are distributed. It challenges the way we think up what we want to study. It challenges us about what questions to ask, who of, where and how. It deeply challenges what concepts and theories we develop. It challenges us (all of us) to look outside the taken for granted boundaries of our professional training and taken for granted assumptions about who is the expert and who is not.

It is wrong to believe that there is not knowledge out there about how to do consumer driven, consumer perspective research. In many countries, especially in Africa, South America and the Sub-continent; and in some disciplines such as development studies this form of research is the taken-for-granted method of first preference. It is a political matter that it is not so in a health context in Australia.

I will admit straight up that I feel unsure about what is happening here today. It feels a bit like the seven of us here who come from and with a consumer perspective are kind of like an embryonic feminist movement and we've come to a workshop to talk about feminist research and find that the workshop has been organised by a committee that is predominantly made up of men and that the ratio of women to men participating is 7 to 28.

Consumer perspective research is not just about adding a pinch of consumer to unchanged and unchallenged research assumptions, and stirring like mad. That cake will flop.

I'm concerned that we have a workshop today which has principles tabled before we have even met. I think that we need to be very careful and not just swoosh through an overladen agenda without due reflection and humility. To do this there are some preliminary understandings we need to have reached and shared:

⊭ We all need to have an understanding of the importance of consumer perspective participatory research;

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- We also need to have an understanding of the methodological and substantive political debates which have taken place within mainstream research and some ideas of our own about how consumer perspective participatory research can penetrate the establishment; and

- We also need to have an understanding of consumer perspective participatory research as part of a growing consumer movement.

In a paper presented at a recent conference, David Webb, a consumer thinker and author describes the limitations of what he calls, 'flatland science'. This is a science that reduces individual consciousness down to observable behaviours and thus fails to truly understand the 'hardest part' which is the meanings for consumers.

Webb argues that consumer perspective research needs to be able to access what he calls, 'first person data'. This he describes as the essence of the lived experience translated **by consumer researchers** into language and conceptual pictures that can be understood by non-consumers. He argues that 'first person methods' have for too long missed out on research development funding and are now the area that needs funding priority. Taken for granted methods of 'traditional science' are useful and, indeed, important but they are **not** sufficient. Kathy has kindly copied copies of David's paper for people to take.

I Finally I want to talk quickly about a piece of work I was involved in 2000 - 2001. I will use this as a small case study.

On the surface the study looked like a pretty standard piece of quantitative research but we added two additional feedback loops on to the stem of the research process. In the first loop researchers (a psychologist and an occupational therapist) went back to the people who had been involved in the initial study (all with a diagnosis of 'Schizophrenia') and fed back to them how they had gone and what the research had found out about them. **They realised that even though finding out about individual people was NOT the purpose of the research it was an inevitable consequence of it.** In the second loop two

consumer researchers were employed to interview participants about their experience of the feedback.

What was so interesting about this piece of work was that over half the consumers the consumer researchers spoke to believed that what they had experienced during the stem of the research **was** a pass/fail test or exam. The researchers had, to their credit, anticipated the possibility of this and hoped they had very clearly explained that the research was **NOT** about passing or failing an assessment.

When interviewed by consumer researchers, however, participants showed very clearly that with all the best efforts in the world the initial researchers' explanation of the meaning of the exercise was not 'heard' by many of the participants. Even more importantly most of these people who understood what they had experienced as a test had simply assumed that they had failed it because of a dominant life experience of 'failure'. When interviewed by the consumer researchers people felt able to speak and they told us that the best thing about the feedback from the researchers was that the researchers were able to honestly tell them how they had gone and they had realised that they had not failed anything.

The importance of this story is:

⊄# Firstly there are real ethical issues for researchers in this tale. How many other people with a 'mental illness' might have had their self esteem further knocked about by 'innocent' researchers undertaking research tasks before they are adequately trained by consumers to do so;

⊄# Secondly, it demonstrates that no matter 'how quantitative' the research is feedback processes to consumers are essential and that this should start to inform a new ethic in relation to mental health research;

⊄# Thirdly, consumers need to be a part of the process from the beginning. This particular project was hampered because there was great difficulty

getting the money to fund the final (consumer controlled) loop of the research. This raised some significant ethical problems for the research team but in the end the project had to start with out consumers researchers on board and

> There are real ethical issues for researchers in this tale. How many other people with a 'mental illness' might have had their self esteem further knocked about by 'innocent' researchers undertaking research tasks before they are adequately trained by consumers to do so

then bring them in much further down the track. This was far from ideal.

≠# Finally, once on board, the consumer researchers immediately sensed there would be an issues about seeing the research as yet another 'exam to fail'. Because of their own experiences of battered self esteems they intuitively suspected that others who had been through some of the same sorts of experiences might think in the same sorts of ways. That is, their hunch (hypothesis) was tested by this double loop feedback and was strongly supported by the data.

You will see reference to the paper we wrote on this piece of work in the blurb about me in the packages everyone was sent prior to this workshop.

I will now pass you over to Yoland so that she can tell you a bit more about the Understanding & Involvement Project which was from beginning to premature end, a consumer-driven major VicHealth-funded research project.

Box 1

A writer of some acclaim is Julie Shaw. She has a particular interest in the history and philosophy of science and has written several important papers that have been published in 'consumer friendly', 'consumer acknowledging" publications. At the Mental Health Services Conference in the late 90s Julie wrote a paper titled intriguingly, "The Rat Speaks Back". At the end of her presentation she concluded with five consumer perspective commandments for researchers working in the area of mental health. They were:

Honour the personhood of the other;

A robust consumer perspective should inform research about 'consumers' and 'mental illness' (and you can't have a consumer perspective without employing real live consumers);

All peoples' time is valuable and should be generously remunerated;

Thou shalt not rob the creative output of another; and

Thou shalt acknowledge those elements of vicariousness and voyeurism which inform your work.

2.4   Consumer directed mental health research: II

Yoland Wadsworth

Adjunct Professor, Swinburne Institute for Social Research

In this presentation Yoland Wadsworth continues to describe and illustrate the model of consumer driven research drawing on her extensive experience of involvement in 'consumers' own mental health research', particularly in the U&I project carried out in Victoria. Her analysis of the key indicators for success of consumer driven research are instructive. These are a critical mass of consumers, independent resources and funding, and a 'consumer place' to return to restrengthen the consumer perspective. Her discussion of the fragility of this model in the face of management change raises issues of critical importance to the consideration of funding and implementation models for consumer driven research in service or organisational contexts.

I want to start by acknowledging that in this room there are some people who have been working in this area on a long-standing basis, some going back decades. I also wanted to say that this work that Merinda and I are talking about is perhaps in a slightly 'different place' to some of the other mental health research work being discussed today. I realised when I read through the material for the seminar that there was a conversation going on about consumers being

involved in other people's mental health research, but in my own experience as a researcher I was involved in consumers' own mental health research. So I am speaking from that experience. I thank Kathy, Merinda, Cath and Alan (who is not here) for wanting me to come and speak about this today, because I don't speak about this work (independently of consumers) and haven't for many years. For me it is chance to come back and look again at this piece of work, in which I was employed by a peak mental health consumer organisation over a period of 8 years to assist them to do their own mental health research. The research was both methodologically sophisticated and also had quite remarkable results.

Indeed, some of those results were so remarkable, that during the period of the time that the project worked it won various national awards. However at one point, a psychologist referred to it as 'propaganda' and I was really shocked by that. Right from the beginning I, as a researcher, had been busy recording and writing and making sure that the material could go into the public domain and the evidence was all there about how exactly all the achievements and conclusions were reached, and so on. The Victorian Health Promotion Foundation has said it was the most extensively written up and published study they have ever funded. What I think the psychologist didn't know, (and perhaps there is still another paper left out of this work to say what really went on behind the scenes to produce that extraordinary work), was that I felt like I was being admitted to a hidden world - of hidden ability, of brilliant capacity - amongst consumers. I think that was because it was on consumer's grounds. It wasn't my research. I've since moved into academia. I haven't been in academia for most of my career and now I've tried to do a piece of work from an academic setting, and it's really impossibly difficult because it is your research. You are seeking people to partner with you. In this work it was the peak consumer organisation, some incredibly insightful, smart people, who were trying to bring in researcher expertise to assist them on their ground. So, it went from being the 'Royal we' as in 'we the scientist' – 'we report on our findings and our research' - to being an 'achieved we' where,

> *I felt like I was being admitted to a hidden world - of hidden ability, of brilliant capacity - amongst consumers.*

literally we worked around tables to assist the process of inquiry to go on, and to have those remarkable outcomes.

The conditions for its success commenced right from the very beginning, throughout the 80's and the 90's, when this long sequence of work (over about a decade) took place. It was a period of an increasing and general world wide upsurge of refusal by marginalised and minority groups to go on accepting exclusion. When I was first employed by the Victorian Mental Illness Awareness Council were DRC, the Resource a major focused activity. I

Consumers are really deciding whether this research is in their interest or not. And choosing the questions for the research, working all the way round that classis cycle on research, choosing what kind of methods, what kind of analyses were made, and so on

(VMIAC), they housed in the Disability Centre, which was hub of really, and intelligent don't know how to stress enough that these initial conditions - which were then echoed throughout the U & I study - were for me the critical ingredient is achieving participation of consumers in research. Consumers are really deciding whether this research is in their interest or not. And choosing the questions for the research, working all the way round that classis cycle on research, choosing what kind of methods, what kind of analyses were made, and so on.

I acknowledge there is a difficulty for research funders who are funding work that meets these kinds of conditions. I'd like to acknowledge the risk-taking of the Myer Philanthropic Trust who put some money in to begin with, saw an excellent result and then Vic Health became involved with providing a major research grant; and after that the State Government department kicked in with further funding.

The three conditions for success, if I tried to isolate them and extract them, are:

- ⍁ A critical mass of people identifying with a 'critical reference group' or critical perspective, i.e. consumer perspective. Not one on their own, or a few, it is a critical mass of people identifying in this way.

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- Independent resources and funding. Whether that is meeting space, office equipment, discretionary funds, grants etc - that the consumers' group is able to organise in their own way, for their own purposes, by themselves, for themselves.

- A consumer place and group for people to return to, to keep restrengthening their perspective. I saw the result of that in terms of debriefing and reversing the endless amount of stress that people encounter when they work in the system. It also meant being able to invite in others who are not consumers (and don't have necessarily the strongest of perspectives), but who had other expertise or resources that that consumer critical mass wanted to access, use and sustain long term in loving and respectful collaboration with other researchers, professionals, service providers, funders and so on.

Those three criteria that I think lead to that capacity to enter into a dialogue with both grace and energy.

The project itself has been well written up and in such detail that I will only skim through this. Some of you are very aware of it because of its prominence over 8 years, and some of you who are newer won't know of it because of its premature demise. The final write up is all in a neat little compendium that Vic Health kindly funded called the *Essential U & I*, the title being an acronymic play on the words 'understanding and involvement' applying to consumers and staff – from either perspective. You can buy it through the Vic Health website.

As I said the project actually began before the U & I project, and I just want to briefly mention the first study Unlocking the System. These are all VMIAC research projects emanating from, of course, an organisation of active consumers. In the first study they employed a non-consumer to do something that was, in a way, conventional research, with a report 'about and with' consumers. This was followed by a second project, which began more of a dialogue called Understanding Anytime. You will see 'draft permanent' written up here in the corner denoting how all this work was seen as ongoing 'work in progress'. This

was about consumer evaluation at an acute psychiatric hospital. For this work, VMIAC employed Maggie McGinness, and she worked more with getting closer to a research design that involved consumers in speaking for themselves. My relationship to these two studies was in terms of working as a consultant to the VMIAC - on the understanding that I came in as a consultant to design research methodology that would begin that transfer to direct service users.

This project then came to an end and was the basis for the major research grant from Vic Health and it was now opening up from the first work, which was **a** consumer evaluation of an acute psychiatric hospital practice per se, to being consumer evaluation of an acute psychiatric hospital practice per se. So it was opening up that discussion. This was research that began in a sense to take this dialogic design - that had come from the first study - and 'scale it up' system wide. I want to say here that this is also research that moved from being research 'of the system for consumers' to 'with the system by consumers'. Consumers weren't interested anymore in just telling about their experiences, they wanted to work with staff, and they sought staff at a hospital that would work with them. And this particular psychiatry hospital came forward wanting to do that. There were staff who then continued to work with the process until it spread right throughout the whole hospital. The project began very much in one ward and then found – to address and improve any individual patients' experience – it needed to move up and out to all wards, the whole hospital, then the regional area to state wide and finally it ended up with national and even international consequences.

My role here was also to work as a design consultant, but now the organisation also employed a consumer as a research officer, which was an interesting advance. And bit by bit we employed another 15 or so consumer consultants who worked on this research. It continued on into some subsequent work which I want to mention and acknowledge: the Lemon Tree work and the Lemon Pip's work. Why I want to mention that very briefly is because my role as a researcher through this work, was as an active design consultant, constantly working with the project that we built, building this dialogue into the whole system. I was

needed to do a particular job, which I took up, which was also as writer. My writing went through consumer editing, but with the work that has come since, the writing task as well has been taken on by consumers. There's Merinda Epstein and Julie Shaw's work, the Lemon Tree work and Cath Roper's stunning piece of work that you should all get a copy of at Melbourne University, and John Kroschel's work at the Alfred Hospital.

Looking in more detail at the dialogic research design of the first Understanding Anytime study - Maggie McGinness could have come in and just asked staff about their views about how to involve consumers, and what consumers thought and written that up. But consumers didn't want to give their views in yet another questionnaire, they wanted instead to tell the stories through their own experiences of coming to the hospital, of being there and leaving. They wanted strategic questions asked also of staff, not just what they thought about what should happen, but what were staff trying to do to assist this to happen? What successes did the staff have? What were staff up against? What were staff trying to achieve in the everyday? And the big picture? and so on. This material was then swapped between the two groups so consumers saw what staff were trying to achieve, and staff saw what consumers thought of the kind of experiences that they had. This was an extraordinary kind of honeymoon phase, with each starting to see how the other sees the world. Staff looked at consumers experience and thought 'that's fantastic, consumers don't think it's all bad'. They had an enormous fear about the horrible, dark things actually being absolutely the whole experience, but it's not and consumers saw what staff were trying to do and were pleased and interested in that. Then it came to a point where consumers were saying 'well we see what you've done here, we can see how hard it is and what you're up against and so on, but we would like it to change. And these are the kinds of ideas that we now have about what could happen'. Then this research stopped at the point where staff were in a sense saying one of two things in response (as follows):

In this cartoon, one staff person is saying 'we must hear from consumers and listen to what they say' and the thought bubble says; "gee that would be hard

and anyway I'm pretty clear that I can see what they would want to say'; and the other staff person is saying 'we can't possibly with so little time…' (Here are also all the defences) – 'there is no point, you can't do anything about it, they are in crisis right now, they might complain, and we are stressed enough as it is, they wouldn't be representative and we're doing the best we can'. And then the thought bubble says; 'gee I wonder what they do think'. So this expresses the paradox at the end of that project, which the Understanding and Involvement project then went on to focus on.

Ironically, as I mentioned, in an attempt to present all the evidence necessary to convince others, the Victorian Health Promotion Foundation has said that this is the best written up and published research project that they have ever funded, yet it all comes down to that dialogue, the simple thing of people speaking to each other. So it's not only consumers' feedback, it's talking about it 'around the table'. Consumers and staff being supported to come together in various sites. We identified three sites. The **consumer-only sites** strengthen consumers coming to this table with staff; the **deep dialogue sites**, where away from the busy decision-table and staff together

> *The Victorian Health Promotion Foundation has said that this is the best written up and published research project that they have ever funded, yet it all comes down to that dialogue, the simple thing of people speaking to each other*

everyday making consumers can come and talk more deeply about how things should be. And those **daily decision-making sites,** at all different levels, drawing on all the different methods and techniques and involving all the different consumers and staff; the resourcing, supporting – all this we "built" into what was the natural organisation culture. We saw this as being the quality assurance framework (which later became a quality improvement approach) - across the whole area of mental health services. It also included supports for staff - the missing "fourth site" - where staff support staff. With researchers assisting to make this happen in all these sites, and researchers also "building in" all of this through an emergent research design.

Let me simplify and then elaborate a little the theory we developed of the paradox, as one of 'wanting to hear, and *not* wanting to hear'. There are an enormous number of ways in which I think we protect ourselves from this. In this context I want to acknowledge the strength of consumers. When I first came into this project I didn't understand this, but consumers kept saying we want to look at the acute experience. And all around us, we had the entire system saying, 'Oh, that's finished, old hat, we're in to the community now, we're not in the institutions anymore. Don't look at that, look at this marvellous community stuff out here'. And that was all wonderful and true, but in the end the power of this project was that it got deeply into this (pictured) business of people going about their business in an acute mental health service system, where the culture is such that the 'hard and heavy' becomes an 'un-discussible'. Everybody in this room knows what the core of the difficulties are, and why this area is such an advanced front for the involvement of consumers, just as the Indigenous research area is an advanced front for the Indigenous people. Where that damage is deepest and violent, it calls forth exactly the marvellous responses which will be expressed by this workshop today to try and right these wrongs. Yet, the paradox: "we want to hear, we don't want to hear" typically means we want to guard ourselves

Everyone from the highest to the middle to the bottom of the entire system was literally coming along, agreeing to the next step. And at the end a bit of the wider system came in that went 'what? You are doing what?' 'You are employing consumers as staff consultants? Oh, we'll take that off you'. And they did.

from that, so that it will go on being a persistent problem. For example, at the end of this project a couple of new managers came in. I don't want to talk about those particular managers, because it was a systems' response. It is the same as would happen anywhere. And in a sense we had come a long way and what happened was a kickback (from a system that hadn't in its entirety come such a long way). But it was nevertheless disappointing to have tried really hard throughout the project to make sure that we never took a step without every player in at least the local and regional system being in support of it. You'll see in the book that all the way along, everyone from the highest to the middle to the bottom of the entire system was literally coming along, agreeing to the next step.

And at the end a bit of the wider system came in that went 'what? You are doing what?' 'You are employing consumers as staff consultants? Oh, we'll take that off you'. And they did. The department took the project and implemented it themselves, and it all comes back to these fundamental three conditions of not seeing the value of the consumer-only organising, and the supporting resourcing and funding for consumers as part of every project or every program, and the need to always have a critical mass of consumers who work together (not isolated from each other) for their own purposes, by themselves, for themselves, using their own independent resources. And that was what we achieved in the project, and that was often the first to go.

But in the end people who are not consumers don't necessarily know what they don't know, and so you need to establish conditions for and with the consumers. They need to be able to speak and speak freely in research, in whatever we are doing. So that voices can be spoken truly and safely, and that the hidden knowledge can begin to be safely shared across a boundary, to involve more and more people who are genuinely beginning to want to hear, and be able to hear.

2.6 Implementation models for consumer participation in health research

Beth Micklethwaite

Research Project Officer,

Consumer Health Forum of Australia

It is 3 years since the publication of the Statement of Participation. In this presentation, Beth Micklethwaite describes a project designed to implement the statement in two research organisations. The difficulties involved in finding suitable, willing participant organisations for the pilot sounds a cautionary notes as does the message that one model does not fit all and the approach needs to be tailored to local context.

Well as Suzanne Northcott told you all this morning, a couple of years ago the Consumers' Health Forum and the NHMRC produced this *Statement on Consumer and Community Participation in Health and Medical Research.* It is very much an overriding principles document and the project that I am working on at the moment is about trying to put that into practice. So I am going to talk to you about some of the things have cropped up. It is a one-year project and we are about 6 months into, so it is unfinished but you can get a sense of where things are going so far.

For those of you who don't know the Consumers' Health Forum is a national organisation. It represents consumers and health care issues. It has a membership of about 100 consumer groups. It really seeks to ensure that consumers shape policy and to ensure that their voices are heard. The background is that the *Statement on Participation* was developed as a partnership between researchers and consumers and a lot of those principles that you see are the bits that people agree on

What we are looking at is the involvement of consumers from the very beginning to the very end.

and so some of those may not be as clear as you might like, but that's what was worked out through the partnership. It does envisage consumer participation at all stages of the research process and one of the things that has been quite interesting talking to researchers about consumer participation, is the sense that 'well I've involved them by getting them to consent in participating in the trial' or something like that, where really what we are looking at is the involvement of consumers from the very beginning to the very end.

These are some of the things that CHF has agreed to do in this project:

⊯ develop practical approaches to implement the statement at two pilot sites

⊯ produce a model framework for consumer participations in research

⊯ develop a resource pack to support consumer participation in research

⊯ evaluate the project.

Just a couple of comments on that: A model framework does not have one size that fits all, so we need to develop a framework that can be adapted locally. The resource pack was initially a pack to support consumer representatives involved in research but consumers have said they also think that researchers need something to help them as well. So its becoming more of a generic kind of thing that would provide guidance and background resources for consumers and also help research organisations in their efforts to involve consumers and help them

avoid falling into some of the common traps. It is also to raise awareness of the *Statement on Participation* to researchers and consumers. My project is overseen by a Reference Group that has representatives from the NHMRC's Research Committee, Australian Health Ethics Committee and the Health Advisory Committee and also has consumer representatives as well.

One of the first things we had to do was select the sites and we rang around quite a few research organisations to see whether they were in interested in participating. We had some selection criteria drawn up by the Reference Group. And these are just some of the criteria that proved to be most important:

⫝̸ They had to be committed to the principles and committed to doing this across their whole organisation, not just the little bits that seemed to fit easily into consumer participation.

⫝̸ They had to involve the whole of their organisation.

⫝̸ There had to be commitment at a very senior level because I am obviously based in Canberra, working with sites in different areas of Australia and you really do need somebody locally who is committed to making this happen.

It was very interesting ringing around different research organisations and getting a very mixed picture. Some places really did not understand the concept of consumer participation in their work and especially if they were mainly involved in basic science. Some felt very uncomfortable with the whole idea of it and saw it as a threat to their research and their funding. Some places had very keen and enthusiastic individual researchers but they couldn't convince the rest of the organisation and we decided that we didn't want to work with places where the organisation was not committed as a whole.

So the sites were chosen by the Reference Group. CHF drew up a collaboration agreement with them which outlined what we expected from them and what

CHF was going to provide, which was basically my input. I could go to each site three times and work out a plan with them based on discussions with the researchers and consumers at each site. I could develop the resources to support consumers and participation locally and provide some training. The sites that we chose in the end were:

⊈ Queensland Institute of Medical Research in Brisbane

⊈ National Ageing Research Institute in Melbourne

We had been looking for sites that would provide a contrast and these two certainly do. They are very different places. In Queensland they have a very large organisation, it is one of the largest in the Southern Hemisphere. It's pretty big. They have very strong connections with the NHMRC. The deputy director is the chair of one of the principle committees of the NHMRC, so there is a lot of connection there. They have a very clear organisational structure to make the work happen. They haven't really had many consumer links in the past, they've provided tours of their facilities, the researchers have gone out and given talks to various community groups but that's really about trying to raise funds for the organisation rather than trying to involve consumers. They also have a very wide range of research interests and given that we are working across the organisation that has made finding consumers quite a challenge.

The National Ageing Research Institute is much smaller and it's more distant from the NHMRC. It does receive NHMRC funding but it doesn't have the same close connections that QIMR has. It's emerging from a period of fairly intense organisational upheaval and as its name suggests it focuses on research into ageing. So, that's made it a little easier to identify consumer groups because there is more of a particular focus to their work. They have had consumer input at board level for a number of years from Council on the Ageing and they have a volunteer network of about 500 people who are involved, either by sticking their hand up to have some blood taken or to stuff envelopes in the office or something like that. So they could use that network as they have already

indicated that they are interested in research in ageing and they want to help with it. So that gives a good opportunity to build networks there.

The CHF and NHMRC are doing this project by building on previous work to develop the statement. But for the sites it is all very new. Some of them may not have heard of the *Statement on Participation* before this work. And when it happens it is received in different ways. …. [missing due to end of tape]. You will be very familiar with a lot of these attitudes I'm sure. These are the sorts of things that have come through so far: We obviously also have sites where there is bit of a focus on making it happen so we may have a bit of an atypical group of researchers there. Some of them are very willing to do it and very convinced but not sure how to go about it. They are scared of getting it wrong, so that has made me think that the model framework really needs to be very practical. Some researchers aren't very sure about what benefits consumer participation will actually bring to their work. It is new territory for them. It is not something that researchers have particularly trained in so I think there is a bit of fear about doing something new. And there was also a senior basic scientist who gave a lay talk to consumers about 12 months ago and described it as being the most terrifying experience of her whole career, which was quite surprising! Researchers are also very wary of the extra time and resources that would be required. There is also a bit of a fear of 'militant consumers' that is coming through quite strongly. Some researchers see consumers as political lobbyists with an axe to grind and the *dislike* of this word 'representative' has really come up quite a lot. They much prefer talking about community perspectives, the word consumer seems to be a frightening one and the word consumer representative seems to be very intimidating. And I am still unpacking why that is, I think for a lot of researchers they first came upon lobbying in the form of animal rights activism and I don't know whether that has had a very negative

impact on the way that they about consumer participation but that has certainly been a very common theme from where they're coming from.

There is a wide range of consumers: some of them are very experienced consumer representatives or advocates at a national level, strong interest in research, very articulate and very experienced; some of them are people who had never thought about consumer participation when we contacted them about this project, so we have a very wide range of experience and if we are talking about building a critical mass that is significant and features quite often. Obviously consumers are wary of the impact of research on their lives. They are quite aware of the power imbalance between themselves and the researchers. They are very unlikely to be 'banging a drum' and as we have said earlier on they are trying to bring a consumer perspective to the research that affects them. They're wary of tokenistic involvement and wanting to protect their own energies and be valued for what they do. And we are going to be looking more at this through various focus groups. We are going to be looking at what works and what doesn't; what attitudes do you have; how can we improve the way that consumer participation happens for both researchers and the consumers.

As I've mentioned we have developed some site plans for each place, and I'm not going to go into exactly what is happening in each place because it is still very early but I thought we'd pick up some of the common themes. The very first one is relationships. A lot of making this work, given the fear and the suspicion and a lot of those sorts of things, is the building of good relationships and a trust between the researchers and the consumers. My project is a year long and building these kinds of relationships of that kind of quality is going to take an awful lot longer than that I'm sure. With the QLD site one of the first things was actually finding the consumers there were we've made doing that because none and in roads into through

> *A lot of making this work, given the fear and the suspicion and a lot of those sorts of things, is the building of good relationships and a trust between the researchers and the consumers.*

CHF's network in QLD, and through national organisations who have local

bodies through articles in the newsletters of groups like Self Help QLD. Also through a snowball approach of asking people 'do you know anybody else, do you know anybody else', and building on people who have been interested in the QLD organisation's work in the past and may be interested in getting involved now. We will probably be starting with some smaller things first to build up those links and they would be things like researchers giving talks as part of their setting up programs of speaking to lay audiences. Inviting consumers along to ask questions about the research, inviting consumers to speak about how it is for them as part of the research and seminar program. I will be going up there again in July to do some training for the consumers that we identified and we are also trying to build in training for the researchers and finding researchers who are very good at involving consumers in their work and inviting them to speak at seminar programs and pass on some of that knowledge.

At the Melbourne site, as I said they've got this volunteer network already. They've never really used it for the sort of thing that we're talking about but the body of people are there and what we would like to do is build on that. The sort of things are the relationships, starting with the places where there is common ground and then working with what people are willing to do at the moment, but also to keep pushing to do more but not try to do everything right from the beginning.

We're adding more information about the project to CHF's website at www.chf.org/au/projects/research, so that would be the place to find out more about it.

Discussion

Norman Swan: Tell me how it works because it is relevant to mental health research. Virtually all of the discussion we've had now has been about critical aspects, service aspects of mental health. Health service research, providing better services, more sensitive services, less damaging services, etc. But there is another aspect to mental health research which is wet lab, neurobiology,

studying neurotransmitters and so on. How does it work in QIMR where mostly they are doing malaria work, basic immunology, there is only some of their work that has a clear clinical applications. So how are they finding this, because there is a lot of mental health research that does not have an immediate clinical application? How could QIMR work with consumers on how the T-cell functions?

Beth Micklethwaite*: The first thing is that there has been a perception, not only there but with other basic researchers that we've talked to, that they have nothing to do with consumers and they [consumers] would not understand it and it would not make any sense and they wouldn't be interested anyway. It has been felt that consumers would be more likely to be interested in the research that would immediately impact on their experiences. But consumers can trace back the treatment that they are getting to that early stage of research, so often there's been an assumption that consumers are not interested without actually finding out if they are. We haven't actually done anything around it yet except to make that theoretical point but the seminars that I have been talking about where consumers are invited to come and listen to researchers talking about their work would include basic science and people actually putting that into an explanation of the effect that it has on you. I think it will be those kinds of things where we can see where it goes next. It is still very early.

Norman Swan: One of the reasons that the researchers are concerned is that in every grant application they say 'and the relevance of this basic research is that it will find a cure for cancer' and if consumers are involved they are going to hold them to it. That's not necessarily a bad thing!

Section 3: The development of guiding principles for consumer participation in mental health research

After the lectures and a subsequent plenary discussion of important concepts and perspectives, delegates focused on developing an aim and guiding principles for consumer participation in mental health research.

This section

- ⊄# outlines the methods used to develop a series of these guiding principles in the workshop;

- ⊄# details how the principles were refined by the first author of this report afterwards; and

- ⊄# presents the resulting draft guiding principles for further consultation and consideration by delegates and stakeholders.

Aim and guiding principles for successful consumer participation in mental health research

Before considering how to promote active consumer participation in mental health research it is important that stakeholders agree on an aim and principles that will underpin the planning process.

This Section describes the methodology that was used to develop the aim and principles, summarises the four sets of principles developed as a result of workshop group activities, and proposes a draft set of statements comprising an aim and 11 principles that take into account individual group concerns.

Methodology

(a) Planning phase

During the planning phase of the workshop, two alternative approaches for developing foundation principles were considered. The first involved asking delegates to generate principles from 'scratch'. The second involved selecting principles developed for similar purposes and using these as templates that could be modified as appropriate by delegates.

There are advantages and disadvantages to each of these approaches. The main advantage of the first option is that delegates are not constrained (or influenced) by pre-existing work but can develop novel statements that might be more suited to the mental health domain than those developed for a broader health context or for a narrower or different health setting. The disadvantage of the first option is that it may result in unnecessary duplication and reinvention of the consensus activities of previous working groups. Advantages of the template option are that it builds on previous consultation and provides delegates with a departure

point for discussion which may be helpful, save time and result in statements that can be integrated into existing policy frameworks.

In the end, the planning committee selected the second option and used existing statements as a template for the development of a new set of principles for consumer participation in mental health research.

(b) The workshop

Workshop delegates were asked to work in groups to develop principles for consumer participation in mental health research. The composition of the groups, the template principles provided to them and the instructions each group for producing a set of draft principles are described below.

Composition of groups

Delegates were allocated to one of four groups (tables) of eight prior to the workshop. Each group comprised delegates from a diverse range of stakeholder backgrounds and institutions with the proviso that there should be at least two consumers at each table. There was a plenary discussion at the outset of the workshop about the appropriateness of this seating arrangement after one participant suggested that separating consumers across the table could be disempowering for consumers. However, the consumers present (two consumer delegates had not arrived at this point) strongly expressed the view that they preferred and were comfortable with the existing arrangement. One consumer indicated that she felt that it would be marginalising for consumer delegates to be relegated to a table by themselves. Seating was therefore not changed. A group Chair was pre-assigned to each table. It was originally intended that two of the groups would be chaired by a consumer and two by a non-consumer. However, due to the unexpected absence of one of the Chairs for part of the day, there were actually three consumer chairs among the groups. A (non-delegate) record taker was allocated to each table, three of whom were consumers and each of whom is a co-author on this report.

Template statements of aim & principles

Delegates were provided with three sets of statements of principle including: a set derived from the NHMRC/CHF Statement on Participation (2001); a set developed at the University of Sheffield in the UK; and a set amalgamated from the first two sets.

The NHMRC/CHF statements (see Appendix F) comprised the Vision statement and a set of 'guiding principles' from the Statement on participation (2001). The 'principles' were extracted by the first author from 'objectives' or principles that were embedded in the Statement of Participation. The term 'mental health' was substituted for 'health' in each statement.

The University of Sheffield statements (see Appendix G) are concerned with guiding principles 'of successful consumer involvement in NHS research'. The principles were developed in a two stage research project that involved: (1) an expert workshop of consumers and researchers to generate a range of principles; and (2) a national survey of consumers and researchers (using a technique known as the Delphi process) to obtain agreement on the final set of principles. (Telford et al., undated http://www.shef.ac.uk/~sharr/publich/research/coninv.htm. Last visited 5/5/04).

The final set of amalgamated principles, were drafted from the first two by the workshop facilitator Dr Norman Swan and are shown in Box 2.

Box 2: Amalgamated principles (after NHMRC & Telford et al)

The following principles are an amalgam of statements from the NHMRC/CHF Statement on Participation (2001) and principles 'of successful consumer involvement in NHS research' in the UK[1]

The Aim:

That consumers and mental health researchers work in adaptable partnerships based on understanding, respect and shared commitment to research that will improve the mental health of the community.

Principles

1.   Researchers accept that the involvement of consumers at the conception, design and implementation stages of research can add value and quality to studies.

2.   Each partnership will be sensitive to its purpose, the personalities and expertise of the people involved and the environment in which it functions with clearly agreed and explicit roles and responsibilities for consumers and researchers.

3.   Researchers and research organisations, including funders, will budget appropriately for the costs of consumer involvement in research partnerships. This includes educating consumers in basic research techniques, research ethics and statistics.

4   Resources for consumer participation in research should cover evaluation of the participation in terms of positive mental health change.

5.   Researchers will ensure that they have the necessary skills to involve consumers in the research process.

6.	Consumers should be involved in decisions about how participants are both recruited and kept informed about the process of the research.

7.	Consumer involvement must be described in research reports.

8.	The partnership will make the results of research available to research participants and disseminate balanced, accessible information about the research and its results to the community.

[1]Telford et al, undated; http://www.shef.ac.uk/~sharr/publich/research/coninv.html. Last visited 5/5/04

Instructions to delegates

Using the three sets of principles described above each group was asked to work on developing an aim and set of principles that would guide consumer participation in mental health research.   The specific instructions to participants (which were drafted by Dr Norman Swan) are shown in Box 3.

Box 3: Instructions to delegates for developing Guiding Principles

The aim of this session is to agree on a set of aims and rules by which consumer participation in mental health research should be governed. They are operational and intended to apply to all circumstances if possible.

The planning group has used the NHMRC principles and the ones for the NHS in the UK and drafted a set which might be applicable to mental health research in Australia.

The task in this session is at your tables. Look at the draft set of principles and see if anything significant is missing and decide whether anything is wrong. In both situations, it would be helpful if you could either draft a replacement or a new principle remembering the fewer there are the more likely they are to be followed.

> *This is not a grammatical exercise. The intention is not to move around or tinker with words. This is about big stuff.*

Outcomes

At the completion of the individual group discussion period, the Chair or spokesperson for each group reported back to the workshop. Most of the groups chose to base their modified principles on the amalgamated version of the principles.

Although there was not universal agreement within the groups, the delegates of three of the groups were able to agree on a set of principles. Tables 1 to 3 present each of these principles along with comments elaborating on the reasons for the wording or selection of the principles and a statement of the origin of the principle. The fourth group did not produce a set of statements. A summary of their discussion of the principles is included in Table 4.

Aim and guiding principles developed by each workshop group

Table 1. Group 1

Statement	Comments from Group	Derivation
Aim: Mental health research will aim to improve the mental health of the community by increasing participation of consumers in that research by:	This statement is intended to acknowledge the importance of the community and to eliminate the implication that researchers are in control of the research. The statement therefore eliminates specific parties. One participant noted: *'The NHMRC statement is for systems where researchers are in control and consumers are being brought in but we have moved beyond that already; often consumers are doing the research and bringing in research consultants.'*	Reframed & reworded NHMRC/CHF Vision statement
1. Working in adaptable partnerships based on understanding, respecting and shared commitment.	This was considered a principles rather than an aim	Modified from *NHMRC/CHF Vision statement*.
2. The involvement of consumers at the conception, design, implementation, evaluation and dissemination processes/stages of research	The phrase 'adding quality and value' was eliminated as it was felt to be subsumed under the aim. It was felt that all stages of the research process should be specified in the statement including 'dissemination and evaluation' to reflect the importance of consumer contributions to these stages.	Modified from *Amalgamated Draft Principles*, No 1
3. partnerships being sensitive to the purposes, personalities and expertise and experiences of the people involved and the environment in which it	It was felt that amalgamated principle 2 contained two important principles which were most appropriately separated into two statements	Modified from *Amalgamated Draft Principles*, No 2

functions		
4. functioning with clearly defined and agreed roles and responsibilities for consumers and researchers with the recognition that these may evolve over time/the course of the project	As above. The statement was also modified to take into account the fact that roles and responsibilities were likely to be dynamic and to evolve over time.	Modified from *amalgamated Draft Principles*, No 2
5. budgeting appropriately for consumer involvement in research partnerships	The entire mental health research community and all players in it have a responsibility to ensure adequate support/budgeting for training. (see next entry also)	Modified from *Amalgamated Draft Principles*, No. 3
6. ensuring both consumer and non-consumer researchers are supported in understanding relevant aspects of the research projects and consumer ethics in order to fulfill their roles and responsibilities	It is not just consumers doing the learning and researchers doing the teaching and funding. Consumers may have funding resources they can access better than researchers and the latter may need to learn about consumer issues.	Modified from *amalgamated Draft Principles*, No. 3
7.providing resources to evaluate research processes and contribution of consumer participation in order to foster continuing improvement	The original principle was reworded with the aim of removing any suggestion that consumer participation was 'on trial' or under the microscope as to its value. Rather it was intended to convey the intention that the entire research process be evaluated to see if the implementation of consumer participation resulted in optimal benefits for all and to identify where improvements could be made across all research processes in the future.	Modified from *Amalgamated Draft Principles*, No. 4
	Amalgamated draft principle No. 5 already covered by Principle No. 6 above.	*Amalgamated Draft Principles*, No. 5

	already covered by Principle No. 6 above.	*Principles*, No. 5
	Amalgamated Draft principle No. 6 already covered by Principle No. 5 above.	*Amalgamated Draft Principles*, No. 6
8. consumer involvement will be described in research reports eg, process, authorship	Insufficient time to consider this in detail. Points raised included why consider only consumer involvement. Researcher involvement should also be described and acknowledged. It was felt that acknowledging all contributors researcher and consumer alike was the important principle, perhaps implemented through description in a report and authorship where appropriate.	Adapted from *Amalgamated Draft principle* No. 7
9. The partnership will make the results of research available to research participants and disseminate balanced, accessible information about the research and its results to the community.	The group felt that this principle 'looked good'.	Adapted from *Amalgamated Draft principle* No. 8
General comments:	The NHMRC statement is essentially designed to encourage researchers to 'bring consumers into their research world'. It does not address or acknowledge that consumers are also commissioning and doing their own separate research. It is important to ask "What is the purpose of these principles, who are they for?" If they are for everyone, if we want real culture change – how best would they be implemented.	

Table 2. Group 2

Statement	Comments from Group	Derivation
Overarching statement: Consumers and mental health researchers work in adaptable partnerships based on understanding, respect and shared commitment to research that aims to improve our understanding of mental health. The fundamental **value** behind these principles is the support for the involvement of consumers at all stages of research.	Note this group has changed 'that will improve' to 'that aims to improve' and has added a value statement. This group felt that there was a need to improve the quality of mental health research itself, not just the outcome in the community.	Reworded and extended *NHMRC/CHF Vision statement*
1. The degree of consumer participation may reflect the degree to which the research will impact upon consumers.	The group argued that different types of research requires different amounts of consumer participation. An extra principle was therefore added.	New principle.
2. The roles of consumers & researchers are agreed between those involved in the research. Each partnership will be sensitive to its research purpose, the expertise of the people involved and environment in which it functions	The 'environment' was considered important. There was lengthy discussion concerning 'purpose' and it was decided that it is the 'research' purpose that should be mentioned.	Modified from *Amalgamated Draft Principles*, No. 2
3. Research organisations will have a policy on consumer participation in research. Budgets would appropriately include the cost of consumer	The group extended the original guidelines by adding the principle that research organisations should have a policy on consumer participation. Most discussion for this table focused on the issue of budgets. It was agreed that the	Extended and modified from *Amalgamated Draft Principles*, No. 3

involvement in the research partnerships.	budget should include educating consumers in basic research techniques, research ethics, and statistics but should also provide for educating researchers regarding consumer needs.	
4. The partnership between consumers and researchers should be evaluated.	It was felt that the evaluation should include whether the process worked and the value of consumer participation. It should also evaluate whether anything could improve the process of consumer involvement and if so what.	Extended and modified from *Amalgamated Draft Principles*, No. 4
5. The training of researchers should include how to involve consumers as partners in research.	Researchers and consumers will learn from each other's expertise and a formal process to achieve this should be put in place.	Extended and modified from *Amalgamated Draft Principles*, No. 5
	Amalgamated draft principle No. 6 was considered redundant and therefore deleted. The overarching statement already recognized that consumers should be involved in all stages of research.	*Amalgamated Draft Principles*, No. 6
7. Consumer involvement is described in research reports.	The group agreed with this principle but substituted 'is' for 'must be' since the latter was considered too strong.	*Amalgamated Draft Principles*, No. 7
8. The research results are described in easily understood formats and language.	The group discussed format and language and the accessibility of information and agree with Sheffield Principle No. 8.	*Adapted from* Sheffield Principles *No. 8*
9. The partnership will explore appropriate and sensitive ways of making results of research available for research participants and encourage and facilitate dissemination of balanced information about the research and its results to the	The group agreed with the NHMRC principles. It was suggested that NHMRC could make the results available in its Annual Report. It would be useful to provide results to interested groups and community media (local papers, radio etc) thus avoiding the central media which may distort information. .	From *NHMRC/CHF Principle* p. 21& 23

community		

Table 3. Group 3

Statement	Comments from Group	Derivation
1. The involvement of consumers at conception, design, implementation and evaluation stages of research will add value to the research.	The group felt that the original wording 'can add value' was not strong enough. Also as originally written, the statement was not considered to be a principle.	Adapted from *Amalgamated Draft Principles*, No. 1
2. The roles, responsibilities and expertise of all parties within the research partnership will be respected, and will be clearly delineated prior to commencement of the research.	Delegates objected very strongly to the term 'personality ' in the original working. It was also felt that the phrasing could be interpreted as a cautionary tale for overeager consumers rather than a principle. (The new principle omits reference to 'purpose' and 'environment').	Adapted from *Amalgamated Draft Principles*, No. 2
3. Researchers, research organizations and research funding bodies will budget appropriately for the costs of consumer involvement in research partnerships.	This principle generated a great deal of debate, especially with reference to what appropriate funding would be. There was some concern about the cost of consultant's fees if these were to be charged by consumers.	Adapted from *Amalgamated Draft Principles*, No. 3
4.	The group was unable to reach a conclusion about this principle.	*Amalgamated Draft Principles*, No. 4
5. Researchers will ensure they have the necessary skills to involve consumers in the research process and demonstrate an awareness of consumer perspective.	The original principle was extended to include the final phrase "and demonstrate an awareness of consumer perspective."	Adapted from *Amalgamated Draft Principles*, No. 5
6. Consumers should be	The group approved of this principle	*Amalgamated Draft*

involved in decisions about how participants are both recruited and kept informed about the process of the research	unchanged.	*Principle* No. 6
7. Consumer involvement will be described and acknowledged in research reports.	Although they conceded that a description of involvement tends to suggest an acknowledgement, delegates felt that a clearer statement was required emphasising the need for public acknowledgment of the value of consumer involvement in research.	Adapted from *Amalgamated Draft Principle* No. 7
8. The results of research will be made available to research participants and disseminated in a balanced, accessible manner and made available to the relevant communities.	It was felt that there was no need to refer to partnerships in this statement.	Adapted from *Amalgamated Draft Principle* No. 8

Table 4. Group 4

This group did not produce specific principles but engaged in a 'lively' discussion.
Discussion relating to some of the individual Principles was as follows:

Statement	Comments from Group	Derivation
	It was suggested that the principles should place and emphasis on mental health *research* rather than researchers. Thus, 'Mental health research will involve consumers . ' as opposed to "The researcher will involve consumers …'	Overarching
	There was disagreement about how specific the specification of consumer involvement could be. Whereas some believed that that the principle should assert that 'consumer expertise *will* be involved in *all* stages of the research' the	*Amalgamated Draft Principle* No 1

	contrary view was that consumer involvement will vary depending on the research project and that consumer involvement at *every* stage is not practical, possible or affordable. There was a suggestion that the principle should allow for different kinds of consumer involvement depending on the research purpose. The group did agree that there should more than 'token' consumer involvement and that this should be reflected in the use of the term *meaningful* participation. There was discussion as to whether the term meaningful should be defined. However, there was concern this would be difficult and that any definition might be overly restrictive.	
	It was suggested that the words 'the people involved' be replaced with 'participants' and that the term 'personalities' be removed. It was considered that there would be difficulty in specifying agreed roles and responsibilities when the research was emergent (that is, that this information will not be known in the beginning).	*Amalgamated Draft Principle* No 2
	It was considered that training should be provided to both consumers and researchers	*Amalgamated Draft Principle* No 3
	There was some concern that this principle should be omitted as it is redundant (see *Amalgamated Draft Principles* 1 & 2). The alternative view was that it be retained and expanded as it is stronger than Principle 1.	*Amalgamated Draft Principle* No 6
	Should removed word *personal* because this suggests that there should be some therapeutic effect on consumers. The	*Sheffield Principle* No 4

	principle should suggest not therapeutic support but rather support in their role.	

Group 4 (continued)

The group discussion focused on the issues relating to definition of terms, the extent to which the principles should be specific and on questions of the specification of power.

Definitions. There was some concern, but no overall agreement about the need for definitions of a number of terms. For example, it was suggested that the term *consumer* was too general. A different view was that the meaning of the term consumer needed to be defined by the nature of the research and that it could be defined by individuals self-identifying as consumers. It was suggested that in the absence of a definition of *expertise*, the term might be interpreted as referring to professional expertise and that this would confer additional power on professionals. The alternate view was that it was important to leave the term general because its meaning will vary according to the purpose of the research and consumers will have different expertise from researchers. Another concern related to the definition of *partnership*. (What sort of partnership?). Partnerships did not necessarily imply equality. The contrary view was that the term 'partnership' needed to remain general to remain applicable to a variety of circumstances.

Degree of specificity vs generality. There was some concern that the principles were too broad and might enable more powerful voices to dominate. The contrary view was that too much specificity might restrict the flexibility necessary to fulfill research aims. Generality allows greater adaptability and appropriateness with respect to the particular task or research.

Power. There was concern that the Principles do not contain an explicit specification of power and that this might lead to a power imbalance in favour of researchers. It was also suggested that the principles 'read' as though the researchers were the main focus and repository of expertise and that consumers were 'added in'. It was important that different types of knowledge (that is, that of the consumer and that of the researcher) be acknowledged, respected and treated as equal. The contrary view was that the aim was to involve consumers in the most productive way and that some stages of research are assisted by consumer participation and some are not, depending on the type of research enterprise involved. Other comments relating to the issue of power related to the need when considering partnerships to be mindful of/acknowledge the past history of unequal power relationships in mental health and the poor treatment of consumers. It was also suggested that there be a reference to *consumer-initiated* research. If resources were directed to this research, the power would shift to consumers.

Integration of the principles

After the presentation of the principles to the whole workshop by each group, delegates agreed that the first author of this report (KG) would integrate the four sets of principles into one coherent set of statements.

The single integrated set of principles was developed by considering for each cluster of similar items, the principles, their underlying rationale and other comments made by delegates to the group as recorded by the notetaker assigned to the group (AJ, KP, CK, LB). In developing the final statements, KG attempted to preserve the intent underlying the original statements.

The integrated principles

This section presents the final aim and a set of 11 principles together with a brief discussion of the rationale underlying the selection and wording of each statement.

Aim:

To improve the mental health of the community and expand and strengthen the current mental health knowledge base through increased consumer participation in mental health research.

This statement makes no assumptions about the research model, stakeholders or power structure needed to achieve the aim. Nor does it incorporate within the aim, statements that might better be included as principles.

The reframed statement therefore addresses concerns raised by Delegates in Groups 1 & 4 that the draft amalgamated aim and principles were framed from the perspective that researchers are the main repository of expertise and are in control whereas consumers are merely being 'added in'. Further, by including a reference to strengthening the current mental health knowledge base, the statement also addresses the perspective of Group 2 which felt that the aims should not be focused on mental health outcomes alone.

Principles:

1. Research partnerships involving consumers should be adaptable and based on understanding, respect, and shared commitment

This statement does not assume that consumers must work in partnerships with researchers or any other stakeholders. It therefore recognises that consumers currently undertake and will continue to undertake consumer initiated and conducted research without researcher input.

2. The meaningful involvement of consumers at all stages of research including its conception, design, implementation, evaluation and dissemination will add value to the research

This statement incorporates the perspective of Groups 1 & 2 and some members of Group 4 that there is value in involving consumers in all stages of research. For clarification, individual stages are retained in the statement and as suggested by two of the groups, additional stages of research added (evaluation [Groups 2 & 3], dissemination [Group 1]) . The statement addresses the concern by Group 4 that any involvement not be merely 'token' consumer involvement by inserting the term 'meaningful' in the statement. Following the recommendation by Group 3, the phrase 'can add value' is replaced by the phrase 'will add value'. We note that some delegates were concerned about the ubiquitousness of the statement. These concerns may be addressed in part, by the addition of the principle which follows immediately below. Finally, the Principle covers the content of *Amalgamated Principle* No 6, and this principle is therefore not included separately below.

3. The degree of consumer participation may reflect the degree to which the research impacts upon consumers.

This is an additional principle not included in the original amalgamated principles. It was proposed by Group 3 who argued that the relevance of consumer participation is likely to depend on the type and likely impact on consumers of the research conducted. A similar view was expressed by some delegates to Group 4 who felt that it was important to allow for different

kinds of consumer involvement depending on research purpose. The principle has therefore been added.

4. Each partnership will be sensitive to its research purposes and expertise and experiences of the people involved and the environment in which it functions.

Following the suggestion of Group 1 we have separated the original principles into two statements. Consistent with Group 2's suggestion, the term 'purpose' has been modified to refer to the 'research purpose'. Reference to the 'environment' is retained as suggested by Groups 2 & 1. The term 'personality' has been omitted from the statement in response to the strong objection to it by delegates in Group 3.

5. The roles and responsibilities of consumers and researchers will be clearly defined and agreed between those involved in the research and may evolve over time and the course of the project.

The statement has been modified to reflect the perspective that roles and responsibilities should be discussed and agreed at the outset (Groups 1, 2, 3) while acknowledging that they may change over time (Group 1).

6. Budgets would appropriately include the cost of consumer involvement in research partnerships.

The wording of this principle was taken from Group 3 and is consistent with statements from Groups 1 and 2. Consistent with the concerns of Group 1, the statement does not imply that responsibility for budgeting lies only with research organisations and researchers. No attempt is made to define 'appropriately' here (see Group 3).

7. Research organisations will have a policy on consumer participation in research

This statement was formulated by Group 3 as an extension of the principle relating to budgeting. It has been expressed as a separate principle here as it has implications beyond those related to budgeting.

8. To fulfill their roles and responsibilities, both consumers and researchers need support and/or training to understand relevant aspects of research, ethics and each other's perspectives.

A number of groups/delegates stressed that training for consumer involvement necessarily involved the education of researchers as well the training of consumers. It was pointed out that consumers as well as researchers could provide training. The wording of the principle reflects these views. It is broadly based on a statement supplied by Group 1 but has been extended to acknowledge the importance of each stakeholder group understanding the perspectives of the other, an issue raised by Group 2. The statement broadly covers the *Amalgamated Principal No 5* and group variants on it so it is not repeated separately elsewhere.

9. Resources should be provided to evaluate the research processes and contributions of consumer participation in order to foster continuing improvement of the implementation and benefits of consumer involvement.

This statement is adapted from one developed by Group 1 which felt that the original statement was problematic because it appeared to place 'consumer participation' on trial. Group 2 was interested in whether anything could improve the process of consumer involvement and if so what. The principle as expressed above is consistent with both these orientations.

10. Both consumer and researcher involvement will be acknowledged appropriately in research reports.

The original statement refers to the need for a *description* of consumer involvement in research reports. One of the groups felt that a clearer statement should be made of the need for public *acknowledgment* of consumer contribution. Another group (Group 1) emphasised that acknowledging all contributers – consumers and researchers – was the important principle. The statement as it is phrased above takes these points into account. By specifying that the acknowledgement should be in an appropriate form, the current phrasing also allows for different types of acknowledgment depending on the level and type of contribution, and the authorship rules of the journal or other body to which a manuscript is submitted. It also allows for contributers to

choose not to have their names included on a publication as is their right (for example, when they do not approve of the content of the final manuscript; or where they wish to remain anonymous).

11. The results of research will be (1) made available to research participants in an appropriate and sensitive way; and (2) disseminated to relevant communities in a balanced and accessible manner

Groups clearly agreed about the importance of disseminating information to participants and the community. Group 3 but not groups 1 and 2 omitted the term 'partnerships' in this principle. Some consumer initiated research may take place outside of a researcher partnership. In recognition of this, the term partnerships were not referred to in the principle. One potential problem with the statement is that it does not explicitly indicate that dissemination is best carried out with input from consumers. However, the principle that consumers should be involved in dissemination has already been included in Principle 2. Finally, group 2 included a separate principle derived from *Sheffield Principle* No. 8 ('The research results are described in easily understood formats and language'). This has not been explicitly included among the principles because it could be argued that the phrase 'accessible manner' implies this and because there are there are other aspects of best practice in dissemination not documented. Arguably, it would be more appropriate to incorporate the information into strategies for action.

Summary

Since principles were modified and additional statements added, the order of the principles was also modified so that the statements would fit into a logical progression. This reordered set of 11 principles are summarised in Box 4.

Box 4: Draft aim and principles

Aim:

To improve the mental health of the community and expand and strengthen the current mental health knowledge base through increased consumer participation in mental health research.

Principles:

1. The meaningful involvement of consumers at all stages of research including its conception, design, implementation, evaluation and dissemination will add value to the research

2. The degree of consumer participation may reflect the degree to which the research impacts upon consumers.

3. Research partnerships involving consumers should be adaptable and based on understanding, respect, and shared commitment

4. Each partnership will be sensitive to its research purposes and the expertise and experiences of the people involved and the environment in which it functions.

5. The roles and responsibilities of consumers and researchers will be clearly defined and agreed between those involved in the research and may evolve over time and the course of the project.

6. To fulfill their roles and responsibilities, both consumers and researchers need support and/or training to understand relevant aspects of research, ethics and each other's perspectives.

7. Budgets would appropriately include the cost of consumer involvement in research partnerships.

8. Resources should be provided to evaluate the research processes and contributions of consumer participation in order to foster continuing improvement of the implementation and benefits of consumer involvement.

9. Both consumer and researcher involvement will be acknowledged appropriately in research reports.

10. The results of research will be (1) made available to research participants in an appropriate and sensitive way; and (2) disseminated to relevant communities in a balanced and accessible manner

11. Research organisations will have a policy on consumer participation in research

This set of principles is now in a form where it can be submitted to the Workshop delegates for their feedback and/or approval.

Section 4: Moving forward

To our knowledge, the national policy workshop and associated systematic wide-ranging consultation process reported here is the first to address formally, policy issues relating to consumer participation in mental health research in Australia. The challenge now is to maintain the momentum established by this first workshop, to refine and implement its outcomes, and to develop targets and strategies for action.

There are several tools which can assist in this process. First, the draft principles that are presented in Section 3, have now been posted on the *BrolgaNet* (http://brolganet.anu.edu.au) bulletin board to enable its membership to discuss and provide feedback about the principles. BrolgaNet is an online network open to all people interesting in promoting consumer focused, consumer perspective mental health research. The network, which was launched at the end of the workshop has a current membership of over 30 people. Delegates to the workshop will be contacted and encouraged to provide feedback on this forum. To ensure that delegates and stakeholders are informed of future policy developments and progress, relevant material, including any minutes of the policy planning or any other working group arising from the workshop (see below) will be posted on BrolgaNet.

Secondly, the preconsultation survey carried out by Griffiths & Jenkins and reported in Section 2.3 identified several priority areas for action to promote consumer participation in research. These were:

- Awareness and cultural change

- Skills and knowledge

- Networking and communication

- Funding and resources

- Evaluation of participation process/outcomes.

Again, BrolgaBoard can facilitate communication between stakeholders about these priority areas. In addition, it offers the opportunity for stakeholders to communicate and network more generally about research projects and issues of interest (Priority 3 & 1), to develop skills and knowledge through the resource board which permits members to upload and share resources with other members (Priority 2, Priority 3); to post and learn about relevant events and research funding (Priority areas 1 & 4) and to share their experiences of participating in research (Priority 3 & 5).

BrolgaNet, although an enabling tool, is only one means for promoting consumer participation in mental health research. Clearly, there is a need to develop a framework and processes for future policy developments in the area. At the end of the workshop, it was agreed by delegates that the CEOs of the National Mental Health Council of Australia and beyondblue would work together with the Director of the Depression & Anxiety Unit to identify and plan ways of progressing the agenda quickly. The outcomes of the workshop as summarized in this report provides a departure point for the planning group. The first task of the planning group will be to consider appropriate processes and structures for progressing the agenda and to identify, where needed, resources for supporting them.

It would be inappropriate to pre-empt the decisions of the planning group. However, it is clear that one specific priority for the planning group will be to oversee the development of a final set of Principles from the draft principles summarized here. Conceivably this process could involve the planning group or a steering group recruited by the planning group to oversee:

- an appropriate consultation process;

- the drafting of the final principles;

- their endorsement and adoption by key stakeholder groups including consumer and research organisations; and

≠# their submission to the councils or boards of key funding bodies for their incorporation into the application funding and reporting process.

Critical target funding bodies include but are not limited to the National Health and Medical Research Council, the Australian Health Rotary Research Fund and Medicines Australia.

A second priority of the planning group will be to consider ways in which the priorities for action identified in the preworkshop consultation process can be progressed. Since the workshop, some delegates have expressed interest in assisting the planning group to move the agenda forward. One option that could be considered is for the planning group to invite key, interested delegates to establish representative working groups for each of the priority areas. These groups could be charged with developing an action plan for their priority area. The resulting action plans could then be compiled by the planning group for further stakeholder consultation and submission to a second national forum on Promoting Consumer Participation in Research with the aim of delegates modifying, refining and prioritising the plans.

In conclusion, the time is right for stakeholders to work collectively to develop a model for promoting consumer participation in research that will improve the relevance and quality of mental health research and serve as a best practice model for other fields of health.

Appendices

A. Workshop agenda

B. Workshop organising committee

C. List of workshop delegates (alphabetical; by stakeholder background)

D. Preworkshop consultation survey

E. Preworkshop consultation survey: list of participants

F. NHMRC *Statement of Participation* (2001) Vision and Principles

G. University of Sheffield Principles of successful consumer participation in NHS research

Appendix A　　Agenda

Depression & Anxiety Consumer Research Unit
CENTRE FOR MENTAL HEALTH RESEARCH

ANU
THE AUSTRALIAN NATIONAL UNIVERSITY

Promoting consumer participation in mental health research: A national workshop

Proudly funded by:

Australian Government
Department of Health and Ageing

DEPRESSION & ANXIETY CONSUMER RESEARCH UNIT

With additional support from:

beyondblue
www.beyondblue.org.au

MENTAL HEALTH COUNCIL OF AUSTRALIA

Australian Government
National Health and Medical Research Council

Venue:	Lecture Room 3, Kurrajong Hotel, Barton, Canberra, ACT.
Facilitator:	Dr Norman Swan
Time & Date:	9am-5pm. Tuesday June 15, 2004

Agenda

9.00-10.30am　　**Opening presentations**

9.00-9.10am　　Mr Dermot Casey, Assistant Secretary, Health Priorities and Suicide Prevention Branch, Commonwealth Department of Health & Ageing.

Open workshop: The Commonwealth's perspective on consumer participation in health research

9.10-9.20am　　Ms Suzanne Northcott, Executive Head, NHMRC's Centre for Research Management, National Health & Medical Research Council.

NHMRC's perspective on consumer participation in health research

9.20-9.40am　　Dr Kathy Griffiths, Director & Senior Fellow, Depression & Anxiety Consumer Research Unit, ANU Centre for Mental Health Research.

Results of the preconsultation survey: Advantages, disadvantages & priorities for action in consumer participation in mental health research

9.40-9.50am　　Ms Beth Micklethwaite, Research Project Officer, Consumer Health Forum.

Implementation models for consumer participation in health research

9.50-10.00am　　**Whole group discussion of models**

Promoting consumer participation in mental health research: A national workshop

Agenda contined

10.00-10.15am   Ms Merinda Epstein, Policy Officer, Victorian Mental Health Legal Centre, and Adjunct Professor Yoland Wadsworth, Swinburne Institute for Social Research.

Consumer directed mental health research

10.15-10.30am   Whole group discussion

Consumer directed model & other issues arising from presentations.

10.30-10.45am   Morning Tea

10.45-12.15pm   Guiding principles

A whole group discussion of guiding principles for consumer participation in mental health research based on principles derived from the following documents:

(1) NHMRC/CHF Statement of Participation Principles
(2) ScHARR Principles for successful consumer involvement in NHS research

The aim of this discussion is to identify those principles that are applicable, those principles which require modification and suitable wording for these, and to develop additional principles if needed.

12.15-1.15pm   Lunch

1.15-2.45pm   Priorities for action/ Ways of moving forward

The meeting will break into groups to identify Aims and Strategies for the following priorities for action identified from the pre-consultation process:

(1) Awareness and cultural change
(2) Skills and knowledge
(3) Networking and communication

Chairs of each group report back to whole group.

2.45-3.45pm   Priorities for action (continued)

Delegates will form different groups to consider the following strategies:

(4) Funding & resources
(5) Evaluation

Chairs of each group report back to whole group

3.45-4.00pm   Afternoon Tea

4.00-4.15pm   Launch of BrolgaNet

4.15-4.45pm   Wrap up: Where to from here?

4.45pm   Close

Appendix B   Workshop Organising Committee

*Dr Kathy Griffiths (Chair)	Director, Depression & Anxiety Consumer Research Unit, Centre for Mental Health Research, ANU
*Dr Grace Groom	CEO, Mental Health Council of Australia
Prof Helen Christensen	Deputy Director, Centre for Mental Health Research, ANU
Prof Ian Hickie	Director, Mind & Brain Institute, University of Sydney & Consultant to beyondblue
Ms Leonie Young	CEO, beyondblue, Melbourne
*Ms Ingrid Ozols	Chair, bluevoices, c/- beyondblue, MHCOA consumer rep
*Ms Suzanne Northcott	Executive Head, Centre for Research Management, National Health & Medical Research Council
*Phillipa Lowrey	Director, Consumer and Research Policy Section, Health Priorities and Suicide Prevention Branch. Department of Health & Ageing

Facilitator

*Dr Norman Swan	Norman Swan Medical Communications

Workshop Organisation

Ms Claire Kelly	Centre for Mental Health Research , ANU
Ms Kim Pullen	Depression & Anxiety Consumer Research Unit, Centre for Mental Health Research, ANU

*planning subcommittee

Appendix C   List of delegates[1]

Professor Sidney Bloch

Sidney is the editor of the Australian & New Zealand Journal of Psychiatry, and a Fellow of both the Royal College of Psychiatrists and of the Australian and New Zealand College of Psychiatrists. He is also Professor of Psychiatry at the University of Melbourne, Adjunct Professor at the Centre for the Study of Health and Society and Honorary Senior Psychiatrist, St. Vincent's Hospital.

Professor Phillip Boyce

Philip is the Professor of Psychiatry at Westmead Hospital and Head of the Discipline of Psychological Medicine at the University of Sydney. He has been involved in research in various aspects of mood disorders for over 20 years. He has set up and established Perinatal Mental Health Services and has been actively involved in research in various aspects of perinatal disorders in particular causes for the past 15 years.

He is currently President of the Royal Australian and New Zealand College of Psychiatrists. He is the immediate past president of the International Marcé Society (an international society for the understanding, prevention and treatment of mental illness in child bearing).

Mr. Dermot Casey

Dermot is Assistant Secretary, Health Priorities and Suicide Prevention Branch of the Australian Government Department of Health and Ageing. He leads a team responsible for the implementation of Commonwealth responsibilities under the National Mental Health Strategy, a Commonwealth/State Agreement to reform Australian mental health services and improve mental health outcomes and implementation of the National Suicide Prevention Strategy.

He is also responsible for a number of National Health Priority Areas; diabetes, cardiovascular disease and evidence based strategies, asthma, arthritis, cancer and cancer service frameworks, research policy and consumer engagement strategies, and the National Chronic Disease Strategy.

Dermot trained in social work in the United Kingdom and law in Australia. Prior to joining the Commonwealth in 1994, Dermot held several positions as a senior manager in Disability and Family and Community Services in the ACT and NSW Governments. Prior to emigrating to Australia in 1984 he was a senior clinical practitioner and service manager in social work in local government social services departments.

Professor Helen Christensen

Helen is a member of workshop organizing committee. Helen is Deputy Director of the Centre for Mental Health Research, Australian National University and is the most highly cited woman scientist in the field of Psychology and Psychiatry. Helen is also a member of the Executive of the Australasian Society for Psychiatric Research, the chair of the Training and Awards Committee, NHMRC, a member of beyondblue's bluevoices research subcommittee, a member of the Australian Health Information Committee, and past member of the Project Grants Mental Health Panel, NHMRC and beyondblue Research Committee.

Dr. Tere Dawson

Tere is a Senior Project and Policy Coordinator at Health Issues Centre. She has qualifications in social sciences with Masters and PhD degrees in sociology and anthropology, as well as a Master of Public Health. Tere has an extensive research background and has published widely.

Mr. Stephen Elsom

Stephen is the President of the Australian and New Zealand College of Mental Health Nurses and is Senior Lecturer at the School of Nursing at Monash University. His mental health nursing career spans over 25 years and includes research experience in clinical practice and education. His current

major research interest and the focus of his PhD project is expanded practice roles of community mental health nurses.

Ms Merinda Epstein

Merinda Epstein is currently Policy Officer at the Victorian Mental Health Legal Centre and formerly Senior Project Officer, National Resource Centre for Consumer Participation in Health. She is a prominent consumer advocate and consumer researcher. She was joint winner of the Australasian Evaluation Society Caulley Tulloch Publication Prize (1995) and part of the U&I research team that won an Australian National THEMHS Gold Award for Partnerships (1995). Publications include articles such as Creating a Positive Experience of Research for People with Psychiatric disabilities by sharing Feedback (Psychiatric Rehabilitation Journal, 2002). She was formerly a research officer and project coordinator at VMIAC and former member of the National Consumer Advisory Group (Mental Health).

David Grainger

David is the Director of Corporate Affairs and Health Economics with Eli Lilly Australia. David maintains close ties with many mental health and psychiatry research groups including Lilly MAP (Lilly Melbourne Academic Psychiatry), a partnership between Lilly Australia and a group of academic researchers from the University of Melbourne, Department of Psychiatry, the Mental Health Research Institute and the Alfred Psychiatric Research Centre. David has experience in clinical trials of medications for schizophrenia and outcomes research in schizophrenia and depression.

Dr. Kathy Griffiths

Kathy is the Chair of the workshop organizing committee. She is Director & Senior Fellow with the Depression & Anxiety Consumer Research Unit at the Centre for Mental Health Research, Australian National University. Academic Consumer researcher, Kathy is Chair of beyondblue's bluevoices research subcommittee, a member of the bluevoices management committee, a Director of the Australian Foundation for Mental Health Research, and Co-Director of the national e-prevention program. Kathy is currently conducting

a study of consumer priorities for depression research, and is the convener of brolganet, a national network for consumer mental health researchers. Kathy was the recipient of the Australian Society for Psychiatric Research Consumer Research Award in 2002.

Dr. Grace Groom

Grace is a qualified teacher (registered in Queensland) and has been working in health care administration and reform since 1994, initially through the divisions of general practice network and more recently as the CEO of the Mental Health Council of Australia. Grace has worked at all levels of the divisions' network including local, State and National positions. Prior to commencing as CEO with the MHCA, Grace held the position of National Primary Mental Health Coordinator with the Australian Divisions of General Practice Network for 2 years.

Grace has extensive experience in the development of partnerships aimed at improving the quality and continuity of mental health care across all sectors. She has worked with a broad range of people including consumers and carers, professionals, administrators, researchers and Government officials. She has effectively advocated in different forums for improvements in mental health care, particularly through the primary care sector.

Her research interests include change management and mental health policy reform.

Professor Ian Hickie (apologies)

Ian is a member of the workshop organizing committee. He is the director of the Brain & Mind Institute and Professor of Psychiatry at the University of Sydney and is the former CEO of beyondblue.

Dr. Nicole Highett

Nicole is a Senior Program Manager at beyondblue. She has published and conducted highly influential research on consumer and carer perspectives of

depression. Nicole has a background in marketing and evaluation and is responsible for evaluation of beyondblue programs.

Ms Fay Jackson

Fay is the director of Consumer and Carer Affairs for the Illawarra Mental Health Service. She is a well known and passionate mental health advocate both in NSW and nationally. She is a national educator and motivational speaker for the Rotary Health Research Fund and represents Sane Australia to the media from a consumer perspective. In 2003 Fay won the inaugural Australian Rotary Health Research Fund (ARHRF) Medal, the consumer award from the NSW Mental Health Association, and a number of other state and local awards. Fay also lectures at Wollongong University for both the Education and Health Faculties.

Professor Tony Jorm

Tony is the Director of the Centre for Mental Health Research at the Australian National University and Fellow of the Academy of Social Sciences. He has received numerous awards and medals for research. Tony is listed in ISI HighlyCited.com since 2003 as one of the most highly cited researchers in Psychology and Psychiatry internationally over the past 20 years. He is current Chair and Trustee, Beyondblue Depression Research Ancillary Fund Trust, since 2001, a member of the Research Committee of the Australian Rotary Health Research Fund since 2000, a member of the NHMRC Research Committee, 2003-2005, a member of the NHMRC Program Grants Committee since 2003, Chair, Partnerships Working Group, NHMRC Research Committee, and other similar positions past and present.

Ms Christine King

Christine is an aboriginal woman from the Northern Territory. Her mother is a Warumangu woman and her father was a Larrakia man. She is a social worker who has worked in the areas of juvenile justice, project management, community violence, community development, counselling, substance misuse, emotional and social wellbeing, mental health, suicide prevention, aged care and palliative care. She is also the principal author of a number of

subjects for the Charles Sturt University, Djirruwang Aboriginal and Torres Strait Islander Mental Health Program. Christine is in the process of completing a masters' thesis on the "Aboriginal Kinship System – the traditional Aboriginal safety net – informing better practice and policy development in Australia" through the Australian Catholic University.

Christine is the Aboriginal and Torres Strait Islander representative for the Department of Health and Ageing.

Phillipa Lowrey

Phillipa is the Director of the Consumer and Research Policy Section in the Health Priorities and Suicide Prevention Branch. Her current position involves health research policy and work with consumer and carer groups. She has worked in the Department of Health and Ageing over the last ten years mainly in Aboriginal health and primary health care. Prior to working in the Public Service she worked for the Consumers' Health Forum of Australia and the Alcohol and Drug Foundation of Australia. Phillipa holds a Masters Degree in Public Policy.

Mr. Bernard McNair

Bernard holds nursing qualifications in both general and mental health nursing, as well as a degree in Nursing Administration from the University of Technology, Sydney. Bernard has extensive experience in both public and private sector healthcare, at clinical and management levels. Bernard is also a nursing surveyor with the Australian Council on Healthcare Standards (ACHS).

Bernard's current position is that of Group Manager of Wesley Health and Counselling Services Wesley Mission, Sydney. Bernard is active in Mental Health Services at local, state, national and international levels. Bernard was the inaugural president of the Mental Illness Fellowship of Australia, and for five years held the position of secretary/treasurer of the Mental Health Council of Australia. Bernard is currently the National Co-ordinator of blueVoices the Consumer and Carer Advocacy body of beyondblue, the

National Depression Initiative and is also a Board member of Lifeline Australia.

Ms Leonie Manns (apologies)

Leonie is a strong advocate of consumer participation in mental health research. Leonie is the Chair of the Mental Health Association of NSW and a former Member of the Regional Issues Committee, Royal Australian & New Zealand College of Psychiatrists and is also the president of The Mental Health Service Conference Inc of Australia and New Zealand (TheMHS).

Ms Beth Micklethwaite

Beth is the Research Project Officer at the Consumers' Health Forum of Australia (CHF). In 2000/2001, CHF and the NHMRC developed a joint Statement on Consumer and Community Participation in Health and Medical Research. This is available online at http://www.nhmrc.gov.au/publications/synopses/r22syn.htm. Hard copies will be available at the workshop. Beth is currently working on a CHF project, funded by the NHMRC, which seeks to develop strategies for putting the Statement on Participation's principles into practice in two pilot sites, medical research organisations with a willingness to build consumer participation into their work. The project will lead to a practical framework for consumer and community participation in health and medical research and a resource pack for consumers participating in the work of a research organisation.

Associate Professor Harry Minas

Harry is a Foundation Director of the Victorian Transcultural Psychiatry Unit, St Vincent's Hospital and University of Melbourne. Harry leads a research team in transcultural mental health. He is a former member of the Mental Health Council of Australia and many state, national international boards and committees, and ministerial advisory groups. He is also a consultant to the World Health Association; leads a WHO Collaborating Centre for Mental Health and Substance Abuse.

Ms Vera Morgan

Vera Morgan is a Senior Research Fellow at The University of Western Australia's School of Psychiatry and Clinical Neurosciences. Her area of expertise is psychiatric epidemiology, focusing primarily on psychotic illness, and she has a special interest in the use of record linkage between administrative health registers to study psychiatric morbidity.

Vera is President of the Australasian Society for Psychiatric Research and is a member of the National Executive of the Australasian Epidemiological Association. She is on the board of the Mental Health Council of Australia and is chair of the Council's Research Subcommittee.

Associate Professor Rob Morrison OAM

Rob is President of the Royal Zoological Society of South Australia, and chairs the Board for Adelaide Zoo and Monarto Zoological Park. He trained as a zoologist, completed his post-doctorate in animal behaviour at Edinburgh University, and holds the position of Adjunct Associate Professor of Environmental Studies at Flinders University.

Rob has written 42 books and dozens of articles on science matters. A science and environment broadcaster for forty years on television and radio, he has won many national and international awards for his books and broadcasts, including a Churchill Fellowship, the Michael Daley Award for Science Journalism and a Eureka Prize. Together with Dr. Deane Hutton, he co-hosted the long-running national television program Curiosity Show, which screened in 14 countries. Rob is currently responsible for the environmental segments on NEXUS, a television program for Australia's Asia Pacific Service, which screens in 31 countries.

Rob is a Councillor for the Nature Foundation SA and a Governor of the Florey Medical Research Foundation. He was formerly the Chairman of the Anti-Rabbit Research Foundation of Australia, a foundation member of the National Environmental Education Council, Patron of the Canberra Inventors' Association and Chairman of the State Steering Committee of Waterwatch SA.

In 2004 he was awarded The Medal of the Order of Australia for his Services to Conservation and Science Communication.

Ms Suzanne Northcott

Suzanne is a member of the workshop organising committee. She is Executive Director of the Centre for Research Management and Policy with the National Health & Medical Research Council, and has a long-standing interest in mental health issues having played a crucial part in the development of the first and second National Mental Health Plans.

Mr. Ian Oliver OAM

Ian grows oranges and wine grapes in the Murray Valley, at Waikerie, in South Australia. Ian is particularly interested in Community and Regional Development and this interest led to participation in Local Government and Regional Development Organizations. Ian is enjoying his 26th year in Rotary, served as District Governor in 1999 – 2000, was appointed as a Director of The Australian Rotary Health Research Fund in 2001 and is currently the Vice Chairman.

Ms Ingrid Ozols

Ingrid is a member of the workshop organizing committee. She is Chair of beyondblue's bluevoices, a member of the bluevoices research subcommittee, a board member of the Victorian Centre of Excellence for Depression and Related Anxiety Disorders, and a member of the executive of the Mental Health Council of Australia. Ingrid is Principal of Mental Health Information Services Pty Ltd.

Mr. Allan Pinches (apologies)

Allan is a consumer consultant in the Northern Area Mental Health Services (Vic) and former metropolitan journalist. He has a specific interest in consumer participation as an engine for change. He has carried out 'a soon to be self-published research project on some possible strategies to strengthen consumer participation in mental health services' and has written about

consumer research participation. He is/or has been in the 'a consumer member of the Neami Inc and Richmond Fellowship of Victoria boards . . . the Vice-President of Neami Inc … [and] regularly writes articles for mental health publications in print and on the Internet.'

Professor Dimity Pond (apologies)

Dimity is head of the Discipline of General Practice. Dimity has been in General Practice in Berowra, on the northern outskirts of Sydney, for 19 years. She has an interest in teaching, and has been a GP supervisor for postgraduate students, as well as teaching undergraduates and practising General Practitioners. Her research interests include disadvantaged groups: the elderly, those with mental health disorders and the unemployed, as well as ethics in General Practice and models of primary care.

Dr. Prasuna Reddy

Prasuna is a health psychologist and full time academic staff member of the school of behavioural science, University of Melbourne. She has published primarily in the area of cultural issues in diagnosis and treatment of psychological disorders and co-occurrence of depression and chronic illness. Prasuna is an elected member of the Board of Directors of the Australian Psychological Society.

Ms Cath Roper

Cath is a Consumer Academic at the Centre for Psychiatric Nursing Research and Practice, University of Melbourne, conducting research from a consumer perspective. Cath recently published a paper entitled: "The role of a mental health consumer in the education of postgraduate psychiatric nursing students: the students' evaluation'.

Ms Ann Smith

Ann is currently a consumer advisory/policy officer with the Mental Health Council of Australia. Previously she was the South Australian representative for the National Consumer and Carer Forum and is the current Chair for the

South Australian Consumer Advisory Committee and Interim Committee and Chair of the Flinders Mental Health Consumer Advisory Committee. Ann was a member of the Steering Committee consisting of consumers and carers that developed the framework for a new model of consumer and carer participation in South Australia. She is currently studying for a Masters' degree in primary health care and will be undertaking studies in mental health and drug comorbidity.

Dr. Meg Smith, OAM

Meg is an Associate Professor in the School of Applied Social and Human Sciences at the University of Western Sydney. Meg is a high profile consumer advocate, academic and mental health researcher. Meg is a part time member of the Mental Health Review Tribunal and president of the Mental Health Association NSW.

Mr. Tony Wade

Tony is a consumer advocate and the Founding Director of Australia Health P/L. He has previously held senior nursing and management roles in health services; and representative and leadership roles in national and state consumer organisations.

Tony provides consultancy and research services on health services development to many organisations and is a regular participant in multi-stakeholder research projects and teams. He is a member of the Australian College of Health Service Executives & the Australian Institute of Public Administration and of a number of advisory committees in medicines and general practice.

Dr. Yoland Wadsworth

Yoland is Adjunct Professor and convener of the Action Research Program at the Institute for Social Research, Swinburne University of Technology, Victoria. Editor of The Essential U& I (VicHealth) summarising a major sequence of consumer research studies in mental health and acute psychiatric services. Yoland was described by a consumer reviewer of the Essential U&I

as 'arguably Australia's foremost expert on participatory research' and as 'well known for her groundbreaking research and guidance with regard to research methodology for Australian consumers and academics for the last 25 years'. She was the winner of the Australasian Evaluation Society ET and S Award and for a career contribution to the evaluation field and 10th winner of the Caulley-Tulloch Prize for Pioneering Evaluation Literature, for the U&I Studies.

Mr. Keith Wilson

Born in Kalgoorlie, WA Keith began his career as a teacher at Mt Barker Junior High School in 1956. After a brief stint in the Army and a course of theological study Keith was then ordained as an Anglican Priest in 1962 and worked as a Curate in the Parish of Scarborough.

From 1965 to 1967 he taught at secondary schools in London while qualifying as an Outreach Youth Worker. On return to Australia he was appointed Parish Priest in a new Public Housing Estate at Balga in Perth's northern suburbs where he became founding President of the Balga Civic Association.

In 1977 Keith was the first clergyman to be elected to the Western Australian Parliament. He held various portfolios in WA including WA Minister for Health from February 1988-1992.

Keith also has extensive experience working on hospital boards and the community-non-government sector. He was elected Chair of the Mental Health Council of Australia in November, 2002 and was recently awarded a Centenary Medal for services in Government to people with mental illness.

Keith has been married to Angela for 35 years. Their younger son who has lived with a mental illness since he was 12 and is now 31, lives at home after many attempts to find adequately supported accommodation. Their older son, Martin is a film director who is currently making a film for SBS Television.

Ms. Leonie Young

Leonie is a member of workshop organizing committee. She is the CEO of beyondblue: the national depression initiative. Previously she was State Manager at the Department of Health & Ageing in the Northern Territory. Leonie has had extensive experience in the delivery of national health programs throughout Australia.

[1]A small number of delegates (denoted by 'apologies' after their name) who agreed and were keen to participate were either ill or otherwise unavoidably detained from attending the workshop on the day.

List of Delegates by stakeholder background

A. Consumer researchers & consumer advocates

Ms Merinda Epstein, Victorian Mental Health Legal Centre.

Ms Fay Jackson, Consumer & Carer Affairs, Illawarra Mental Health Service, NSW.

Ms Leonie Manns, Mental Health Association of NSW; TheMHS

Ms Ingrid Ozols, bluevoices, beyondblue the national depression initiative

Mr Allan Pinches, Northern Area Mental Health Services, Victoria

Ms Anne Smith, SA Consumer Advisory Committee; MHCOA.

Mr Tony Wade, Australia Health P/L

B. Academic consumer researchers

Dr Kathy Griffiths, Depression & Anxiety Consumer Research Unit, Centre for Mental Health Research, ANU

Ms Cath Roper, Centre for Psychiatric Nursing Research & Practice, University of Melbourne.

Dr Meg Smith, School of Applied Social and Human Science, University of Western Sydney.

C. Academic researchers

Professor Helen Christensen, Centre for Mental Health Research, ANU (Also carer)

Professor Ian Hickie, Brain & Mind Institute, University of Sydney

Dr Nicole Highett, beyondblue: the national depression initiative

Professor Tony Jorm, Centre for Mental Health Research, ANU (Also carer)

Adj Professor Yoland Wadsworth, Action Research Program, Swinburne Inst of Technology

(see also Bloch, Boyce, Elsom, Minas, Morgan & Ready below)

D. Transcultural

Associate Professor Harry Minas, Victorian Transcultural Psychiatry Unit.

E. Aboriginal & Torres Strait Islander representative

Christine King, Department of Health & Ageing

F. Clinicians/Professional organisations

Professor Phillip Boyce, Royal Australian & New Zealand Journal of Psychiatry

Mr Stephen Elsom, ANZ College of Mental Health Nurses.

Ms Vera Morgan, Australian Society for Psychiatric Research

Professor Dimity Pond, Discipline of General Practice

Dr Prasuna Ready, Australian Psychological Society

G. Non government organisations

Dr Tere Dawson, Health Issues Centre, National Resource Centre for Consumer Participation in Health.

Dr Grace Groom, Mental Health Council of Australia

Mr Bernard McNair, bluevoices, beyondblue.

Ms Beth Micklethwaite, Consumer Health Forum

Mr Keith Wilson, Mental Health Council of Australia (also carer)

Ms Leonie Young, beyondblue: the national depression initiative

H. Policy makers

Mr Dermot Casey, Commonwealth Department of Health & Ageing

Phillipa Lowrey, Commonwealth Department of Health & Ageing

(See also Northcott below)

I. Funding bodies

Ms Suzanne Northcott, National Health & Medical Research Council

Mr Ian Oliver, Australian Rotary Health Research Fund

J. Industry

Mr David Grainger, Eli Lily

K. Dissemination

Professor Sidney Bloch (Vic) Editor, Royal Australian and New Zealand Journal of Psychiatry.

Associate Professor Rob Morrison (South Australia) (media expert)

Workshop Secretariat:

Ms Claire Kelly, Workshop coordinator (Consumer, PhD student). Group 3.

Ms Kim Pullen CRU Liaison Officer (Consumer). Group 2.

Ms Affrica Jenkins (Carer, Research Assistant). Group 1.

Ms Lisa Barney (Consumer, PhD student). Group 4.

Ms Kylie Brittliffe, Promotions officer (Consumer & Executive Officer, Australian Foundation for Mental Health Research).

Stakeholder Consultation Survey

"Promoting Consumer Participation in Mental Health Research: Survey of stakeholder opinions"

Please write your answers in the boxes provided. Any information you can provide is appreciated.

Personal Details :
If you wish to remain anonymous do not place your name on this form. Otherwise your identity will be retained and may be quoted with your responses in a report.

Name:	Telephone:
Organisation:	
Postal Address:	Email:

Q1. In your view what are the major advantages of consumer participation in mental health research?

Q2. In your view what are the major disadvantages of consumer participation in mental health research?

Q3. Specify three key, broad priorities for action to increase consumer participation in mental health research.

1.

2.

3.

Q4. Tick /select those boxes that apply to you:

"I am a...

£ a Consumer; If yes are you a £ ai consumer advocate £ aii consumer consultar

£ b Carer; If yes are you an £ bi advocate

£ c academic

£ d member of an NGO

£ e health policy maker

£ f health/mental health provider

£ g journal editor or member of an editorial board

£ h mental health researcher (academic or consumer)

£ i member of a mental health research funding panel (eg, NHMRC panel)

£ j member of an organisation that funds mental health research

£ k interested in facilitating consumer participation research

£ l interested in conducting consumer oriented research

Q5. Indicate your main area of interest (eg, depression, schizophrenia, co-morbidity etc)

We wish to know more about how people are currently working together. The following questions are the ways in which consumers have been involved in mental health research to date:

Q6. Have you been involved a mental health research project, as a researcher and/or consumer?

£ Yes

£ No   (skip to question 9)

Q7. Think of the project you have participated in that had the highest level of consumer involvement. Use the scale below to indicate how much influence consumers had on that research project: 1 = "passive" participant, 7 = project leader.

| | | | | | | |
|1|2|3|4|5|6|7|

1
"passive"
participant

7
project
leader
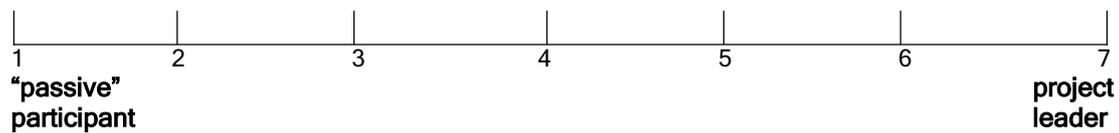
Q8. Please outline the role(s) played by consumers in the research project:

Appendix E   Preworkshop consultation survey: List of participants

The following people identified themselves as contributers to the stakeholder survey:

Ailsa n'ha Winifreyda.   Flinders University

Alexandra Gartrell   Deakin University

Allan Pinches   Northern Area Mental Health Service

Amaly Khalaf   Australian National University & Child and
                               Adolescent Mental Health Service

Ann McBryde   Brisbane North Division of General Practice

Ann Smith   Mental Health Council of Australia

Anne Bevan   ARAFMI (Association for Relatives and Friends of
                               people with Mental Illness), Hobart.

Ans Van Loon   Consumer

Anthony J Hinton-Bayre   Royal Australian Institute for Community Justice
                               and Mental Health Research Development

Beppie Hedditch   ARBIAS (Acquired Brian Injury Service)

Betty Kitchener   Centre for Mental Health Research

Bibiana Chan   Black Dog Institute

Bob Boss-Walke   Hastings Macleay Division of General Practice

Bob Johnson   TAFE

Bonnie Walter   Flinders University

Brian Howley	Mental Illness Fellowship
Bronwyn Hansford	Inner West Area Mental Health Service – Royal Melbourne Hospital
Carole Davis	Charters Towers Rehabilitation Unit
Carolyn Richards	Peel Southwest Division of General Practice
Carolyn Russell	Foundation Counseling and Carseldine Medical Centre
Cath Roper	Centre for Psychiatric Nursing Research & Practice
Catherine Conroy	Infant and primary school teacher
Cathy Sanders	Chair, ACE Division of GP's
Celsete Layton	GMHCUI (Geelong Mental Health Consumers' Union)
Charles Lawlor	
Chris Phelan	Get Together House
Christine Ericksson	
Claire Kelly	Centre for Mental Health Research
Clare Wilson	Edith Cowan University
Creswell Surrao	Clinician Training Program - Office of Mental Health Western Australia
Danielle Elisha	SANE Australia
David Guthrie	Barwon Health

David Webb	Victoria University/ Victorian Mental Illness Awareness Council
Dawn Darlaston-Jones	Edith Cowan University
Debbie	Consumer
Dell Fagg	
Dermot Casey	Assistant Secretary, Australian Government Department of Health and Ageing
Desley Casey	Northern Beaches Mental Health Consumer Network
E. Rinaldi	Consumer
Eric Turnbull	PCMHS (Peel Community Mental Health Service)
Esther Singer	ORYGEN Youth Health
Evan Bichara	Victorian Transcultural Psychiatry Unit
Evelyn Webster	Freelance Consumer
Fay Jackson	Illawarra Area Health
Fiona McDermott	Mental Health Practice Research Unit, School of Social Work, University of Melbourne
Fran Leaupepe	
Gabrielle Savige	Mental Health Association
Georgia Kereopa	Integrated Mental Health Service
Gillian Holt	
Glen Tobias	Neami, Darebin

Grant Russell	Perth Central Coastal Division of General Practice
Harry Minas	Victorian Transcultural Psychiatry Unit
Helen Christensen	Centre for Mental Health Research
Hester Wilce	Private Practice and Kirketon Rd Centre
Ilse Blignault	Centre for Culture and Health
J Anthony Turner	Multiple
James Van Den Bosch	
Jan	Viewpoint Rehabilitation Centre
Jane Bayley	Cairns Integrated Mental Health Service
Janet Meagher	Psychiatric Rehabilitation Association
Janette Curtis	University of Wollongong
Jenny Ouliaris	North East Valley Division of General Practice
Joan Robertson	ARAFEMI (Association for Relatives and Friends of the Emotionally and Mentally Ill) Life Member
John Anthony Decker	Victorian Mental Illness Awareness Council / Saltwater Mental Health Centre Footscray
John Brown	School of Psychology
John Bryer	North Eastern Bipolar Support Group
John Gibson	Greenslopes Private Hospital
John Harrison	
John Snowdon	Central Sydney Area Health

John Stewart Furniss	Out Patient, SouthWest Healthcare Psychiatric Services
Jonine Penrose-Wall	University consultant
Judith Bancroft	Perth and Hills Division of General Practice
Judith Brine	"Consumer"
Judith Walters	Aspire and Dash
Judy Vaughan	
Kate Lemerle	Queensland Transcultural Mental Health Centre
Kerry Geraghty	Mater Child and Youth Mental Health Service
Kim Woolcock	Yeronga Child and Youth Mental Health Service
Kylie Brittliffe	Centre for Mental Health Research
Kylie Griffin	Upper Hume Community Health Service
Lara Bishop	Centre for Mental Health Research
Lawrie Horner	
Leanne Elsworthy	B Miles Women's Housing
Leonie Walsh	Inner West Area Mental Health Service
Les Fishman	
Lesley Nord	Mandala Inpatient Unit
Liam Buckley	St. Vincent's Mental Health Services, Melbourne.
Liz Carr	Victorian Mental Illness Awareness Council
Loretta Foster	Upper Hume Community Health Service

Louise English

Louise Hargreaves

Lucia Fell   Charleville Mental Health Service

M. F. Johnson   M.A.R.I.C

Margaret Cook   AMHCWA   (Association of Mental Health
                              Consumers, Western Australia)

Margaret Johnson   Bettalife Solutions

Mark Lacey   Grampians Psychiatric Services

Mary Anne Lucas   GROW National

Megan Hand

Melissa Bruhn   VMIAC (Victorian Mental Illness Awareness
                             Council)

Michael Dyer   Psychiatric Rehabilitation Association

Michael Fuller

Neil Cole   Mental Health Research Institute

Nick Hillman   ACT Division of General Practice

P Emmett   Consumer

P Farley   Northern Territory ARAFMI (Association of
                             Relatives and Friends of the Mentally Ill)

P. Brien

Patricia Minnaar	Ex-QCAG (Queensland Mental Health Consumer Advisory Group) and Brisbane Obsessive Compulsive Disorder Support Group
Paul Dudgeon	University of Melbourne
Paula Hanlon	Ryde Consumer Network (employed 24hrs Ryde Community Mental Health Services)
Pauline Miles	Western Australian State Delegate for the Australian Mental Health Consumers Network
Peter Pickett	Impact (PSS)
Philip Webster	Ontario Medical Clinic
Pia McKay	Mirrabooka Mental Health
Ralph Hampson	PhD Student
Raymond Ho	Bayside Child and Youth Mental Health Service
Renate Charban	Re-earth
Rita Prasad-Ildes	Queensland Transcultural Mental Health Centre
Robert Craig	G.P. Connections
Robyn Moreland	OE CAT Team Eastern Health
Rodger David Medro	Mental Health Network (Murray and Campaspe)
Ron Barker	Queensland Health
Rosemary Mills	Association for Mental Health Consumers (Western Australia)
Rosemary Thomas	Spectrum

Russell McGowan	Health Care Consumers' Association
Ruth Russell	Ageing & Community Care SA
S.Wald	ACT division of General Practice
Sandra Kippen	La Trobe University Bendigo
Sarah Lawrence	Victorian Mental Illness Awareness Council
Sebastian Hexa Dvortche	
Sharon Cassar	Westgate Division of General Practice
Sharon Monterrubio	University of Wollongong
Sophie Glover-Koudounas	Head, Medical and Scientific Affairs Solvay Pharmaceuticals
Stephen Metcalf	Cairns Consumer Advisory Group
Steve Druitt	Mental Health ACT
Susan Rimington	GARSS (Gippsland Accommodation and Rehabilitation Support Service)
Susan Wearne	Chair, Central Australian Division of Primary Health Care
T.King	CAG (Consumer Advisory Group)
Team Leader	Charters Towers Community Mental Health
Tennant T	Royal North Shore Hospital
Terry Udy	Chairman, Murray Mallee Consumer Advisory Group (Mental Health)
Tony Jorm	Centre for Mental Health Research

Tracy Ray   Volunteer support/counselor worker

Trevor Cookson

Troy S Almond   Continuing Care South

Wilce   Private Practice and Kirketon Road Centre

William Moon

Yoland Wadsworth   Swinburne Institute for Social Research

Respondents who listed their organizations only:

School of Nursing and Midwifery

Flinders University;

Victorian Mental Health Legal Centre;

Goldfields Men's Health Incorperated;

Australian National University;

Mental Health Carers' Network,

South West Sydney;

School of Psychology, Flinders University;

Mental Health Unit, Queensland Health; Belconnen Community Centre;

Consumer Advisory Group Frankston

Other participants responded to the survey anonymously.

Appendix F   NHMRC/CHF Vision and Principles

The following Vision and 'principles' have been extracted from the NHMRC/CHF Statement on Participation (2001). (Mental health has been inserted in place of health.)

Vision:

Consumers and researchers working in partnerships based on understanding, respect and shared commitment to research that will improve the mental health of the community. (p. vii)

Principles/objectives

Consumers and researchers will collaborate and draw on each other's knowledge to build on and strengthen the quality of mental health research. (p. 17)

This collaboration will be achieved through partnerships of consumers and researchers based on mutual trust and shared social responsibility, giving consideration to what each can reasonably expect from the other. (p.v iii; p.18)

Each partnership will need to be sensitive to its purpose, the personalities and expertise of the people involved and the environment in which it functions. (p. viii)

The partnership of consumers and researchers will shape decisions about research priorities, specific research questions and design of research projects in a fair way that recognizes and responds to the rights of all voices to be heard. (p. ix) (p. 20)

The partnership will explore appropriate and sensitive ways of making the results of research available for research participants … and encourage and facilitate dissemination of balanced information about the research and its results to the community. (ix; p. 21)[1]

Consumers' time and expertise needs to be valued in some way, which will assist with a sense of ownership and responsibility and guard against a tokenistic partnership. (p. x)

Consumers and researchers will advocate for the resources needed for effective consumer and community participation in mental health research. (p. ix),(p. 24)

Resources for consumer participation in research should also cover evaluation of the participation in terms of positive mental health change. (p. x).

These statements of principle may be useful as a guide but it remains necessary to consider what is fair and appropriate in each situation. (p. viii)

[1]NB: Modified original as follows: p. 21 states: 'The partnership of consumers and researchers will support the rights of research participants to their own results, be accountable to them for the results of the research, and encourage and facilitate dissemination of balanced information about the research and its results to the community. p. 23 states: 'Partnerships of consumers and researchers using this Statement on Participation will be uniquely placed to explore appropriate and sensitive ways of making the results of the research available for research participants in a variety of different research settings.'

Appendix G University of Sheffield NHS principles

The following principles 'of successful consumer involvement in NHS research" were derived from a consensus study and national survey in the UK (Telford et al, undated; http://www.shef.ac.uk/~sharr/publich/research/coninv.html. Last visited 5/5/04). The methodology involved an expert workshop of consumers and researchers to generate principles which were then evaluated by a wider group of consumers and researchers using the Delphi process to obtain agreement on the final set of principles.

Principle 1

The roles of consumers are agreed between the researchers and consumers involved in the research

Principle 2

Researchers budget appropriately for the costs of consumer involvement in research.

Principle 3

Researchers respect the differing skills, knowledge and experience of consumers.

Principle 4

Consumers are offered training and persona support to enable them to be involved in research.

Principle 5

Researchers ensure that they have the necessary skills to involve consumers in the research process

Principle 6

Consumers are involved in decisions about how participants are both recruited and kept informed about the process of the research.

Principle 7

Consumer involvement is described in research reports.

Principle 8

Research findings are available to consumers, in formats and in language they can easily understand.