

**ENCOURAGING ETHICAL
AND NON-DISCRIMINATORY
RESEARCH WITH
MENTAL HEALTH CONSUMERS**

A Discussion Paper

by Debbie Peterson

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Introduction

I was asked by the Mental Health Commission to write a short paper to promote discussion about, and to encourage non-discriminatory, ethical research in the mental health area.

What follows is not intended to be a definitive guide to ethical issues in social science research involving mental health consumers. It covers aspects which I have identified in my own research, from the literature and from discussion with others, and will, I hope promote the discussion that the Commission wishes to occur. Different research disciplines have their own ethical guidelines, and this paper is intended to complement, not compete with these.

Consumer participation in all aspects of mental health policy, service delivery and evaluation is a major component of The National Mental Health Standards (Ministry of Health 1997). This, and the Mental Health Commission's goal to reduce discrimination against people with mental illness (Mental Health Commission 1998), have influenced the direction of this document. My review of some of the considerable discussion in the literature on the most appropriate research methods and approaches to use with consumers has also had a major influence (e.g. Campbell, Ralph and Glover 1993, Glenister 1994, Rapp, Shera and Kisthardt 1993, Rogers and Palmer-Erbs 1994, Shaw and Epstein 1996).

Many of the points raised in this paper are not new, and will be familiar from a range of different contexts (for example discussions on research with general health consumers (e.g. Daly 1996), Maori (e.g. Health Research Council 1998), people with literacy problems (e.g. Luna 1995). The value that this paper adds though, is to bring these ideas together in a discussion focusing solely on research with mental health consumers.

Debbie Peterson
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Research Can Contribute to Discrimination Against Mental Health Consumers

Research that discriminates against or contributes to the on-going discrimination against mental health consumers can not be ethical. Some of the ways research can do this are by: contributing to stereotypes of consumers; not including consumers in research or research processes; and by discounting consumers' voices and experiences.

Contributing to Stereotypes of Consumers

Researchers sometimes make assumptions about people with experience of mental illness. Two of these are assuming that all consumers are the same, or assuming that all people with experience of mental illness are incompetent.

It may be tempting to assume that all mental health consumers are an homogeneous group. The only thing linking individuals however, is that they have experience of differing types of mental illness or service use, and these experiences vary greatly from one person to the next. The word 'consumer' is problematic in itself, the definition differing depending on both the researcher and the research context. The stereotypical mental health consumer does not exist.

Given that consumers are quite capable of making decisions for themselves most of the time, it is also inappropriate to assume that people with experience of mental illness are always incompetent or have difficulty making decisions. These underlying assumptions can frame the way research is designed, carried out, and written up, further endorsing stereotypes.

A second way that research may contribute to stereotypes is by the use of inappropriate language. Some research labels people with mental health problems as 'the mentally ill', 'chronic', or 'schizophrenic', etc. These terms are dehumanising and contribute to the myth of the existence of a stereotypical mental health consumer.

Not Including Consumers in Research

It is usually considered necessary for groups that will be affected by research to be involved in some way in the design of that research. Despite this, it has only recently become practice to involve mental health consumers in the design of some of the research projects directly affecting them (usually service evaluations). Just as for other groups, if the outcomes of a research project have the potential to impact on mental health consumers, then consumers need to be involved. The extent of this involvement depends on the nature of the project rather than because the participants are mental health consumers.

Involving people with experience of mental illness at the pre-planning (when research priorities are set) and planning stages increases the chances that the aims of the research will be relevant to consumers. As well as

improving the value of the research topic, relevance to consumers improves the likelihood that consumers will want to be involved as participants, potentially improving response rates, representativeness, quality, and outcomes of the research. Asking people to comment on a specific aspect of a research project when, from their perspective, the project is focused on the wrong research question may make the exercise pointless. By not bringing consumers into a project in the planning or pre-planning stages, the chances are increased that they may feel like they are involved only to satisfy the need for a token consumer perspective, not because the substance of their input is valued.

For involvement to be meaningful there may be a need for training and research support to be accessible to consumers involved in planning or undertaking research projects. The more research experience and training consumers have, the more they will have the tools to add value to a research project, and the confidence to challenge discriminatory and unethical practices.

It may be difficult for a researcher to know how to obtain appropriate consumer input into a research project. The decision on which consumers to involve or the process to use is often not easy, and is almost invariably open to criticism (usually around issues of representation). Some researchers contact consumer groups, who, as the obvious point of contact may already be busy working on other projects and thus may be limited in the input they can make. Consumer groups are also not usually representative of all people with experience of mental illness. They provide a valuable perspective on consumer issues, but it is a particular perspective and not the only perspective. Other times researchers will ask someone they know to have a consumer background to be involved. When the research is service based, the most important people to talk to about appropriate consumer involvement in the research process are the consumers of that service. Payment for the time of those consumers involved may also be an issue, as many will not have their salaries covered by an employing organisation.

Discounting Consumers' Voices and Experiences

Good quality research that is methodologically sound and ethically based can be a very effective way of ensuring that consumers' voices and experiences are not discounted.

Some research studies ask mental health professionals or family members about consumer experiences but do not ask consumers themselves (some examples of this are discussed in Glenister 1994). There is no substitute for a consumer's perspective on their own experiences. Others' interpretation of consumers' experiences may be important, but this can be sought alongside of, not instead of consumer perspectives.

The voices of people with experience of mental illness are no less valid than the voices of family or mental health professionals, and need to be

given equal weight. In some studies a different methodology may be used for consumers than for other participants in the research (for example, focus groups compared to individual interviews). The voices of consumers may be discounted if the methodology used for them is given less weight in the research findings. This discounting may also occur if the research discussion dismisses, undervalues, or seeks to explain away what consumers have to say because they differ from other participants.

Reviewing literature is an essential aspect of research and is another area where consumer voices may be discounted. Much of the research undertaken by consumer organisations is undertaken on a small scale, is not published, or is not seen as academically rigorous enough to have a wide or long distribution amongst academic circles. Consequently it is often missed.

The experiences of different groups of consumers need to be recognised, so that all consumer voices are able to be counted. Culturally appropriate research that takes into account the potentially varied backgrounds of participants is essential.

Ethical Approval

Ethical issues need to be considered whenever research is to be undertaken. People who are not researchers may undertake research type activities without realising the need for ethical review. Because questionnaires and focus groups are fairly common-place and are often used as part of consultation exercises, the perception may be that they are easy to do and can be done by anyone with minimal or no research training. 'Research' is often seen as something done by researchers rather than an activity in itself, so the ethical review process can often be overlooked.

Consultation, audits, and monitoring are all examples of activities that may involve using research techniques. Because an activity goes under a different name does not mean that it is devoid of any ethical issues, or that the people undertaking it do not have any ethical responsibilities. The National Standard for Ethics Committees lists audit, monitoring the quality of care, surveys which do not involve the use of confidential or other sensitive personal information, resource allocation, access criteria, and practice guidelines (National Advisory Committee on Health and Disability Services Ethics 1996) as matters not requiring ethics committee appraisal. The standard is quite specific in its definition of these six areas and need to be referred to before deciding that a project does not require ethical approval.

Informed Consent

Traditional discussions of informed consent in research tend to focus on the vulnerability of those using mental health services and consider ways to protect consumers from exploitation. Some researchers deal with this

issue by requiring consent from a third party (a family member or a mental health professional (Association of Social Science Researchers 1996)) as well as the consumer concerned. This gives the message that mental health consumers are incompetent to make informed decisions, and does not take into account differences between consumers and differences in research situations.

Before approaching potential participants, all aspects of the research project need to be assessed to decide the reasonable grounds to judge whether an individual is not fully competent to give informed consent. The time, effort and information required, potential risks, perceived inducements, and the sample selection process all need to be considered. Even consumers subject to compulsory treatment orders may still be competent to consent to participate in research in some situations. The National Standard for Ethics Committees acknowledges that competence to give consent may be affected by a person's mental condition, but stresses that a basic assumption in favour of competence should be made.

Other aspects to informed consent are the factors that influence a potential participant's decision to give or decline to give consent. There may be various risks and benefits associated with a research project that can influence a consumer's decision to participate. Not all of these are immediately obvious. If the research is service related, consumers may feel that their ongoing access to the service may be jeopardised by refusing to participate, or enhanced by agreeing. If the outcome of a research project is connected to the survival of a service, the people using that service may feel under great pressure to participate. The opportunity to obtain new, different, or free treatment may be another inducement to participate, even if there is no guarantee that the treatment will continue after the research has finished.

The opportunity to influence the future of the mental health services, and the chance to 'tell their stories' or 'express their views' may be two other perceived benefits of participating in research. Overemphasising the importance of a particular research project may have a major influence on the decision to participate, especially as mental health consumers have traditionally been discounted as a group, and many feel that their views and personal experiences have not been listened to or taken seriously. Discovering that the importance of a research project has been over-emphasised can have a major influence on a person's decision to participate in future research.

Confidentiality/Anonymity

The discrimination that people with experiences of mental illness face means that it is especially important to respect people's rights to confidentiality in research. Consumers may feel that their responses are not going to be anonymous or remain confidential only to the researcher if there is a link between the researcher and a service provider. It is important

therefore, that clear protocols are decided at the start of a project to ensure that there are appropriate boundaries between research and service provision.

Over-Researching

There is a potential for people with experiences of mental illness to feel over-researched, even if to a researcher, there appears to be very little actual research being carried out. To participants there is very little difference between research, consultation, consumer satisfaction surveys and making submissions - each requires time and energy. Over-researching is less likely to occur if the purpose of the research is clear, the need for it is firmly established, there are identifiable benefits to the participants, and the same people are not being asked the same questions repeatedly.

Using Appropriate Methodologies and Research Approaches

There are no categorically right or wrong ways to do research with mental health consumers. The methods used to carry out a particular research project need to be adequate to answer the research question so that the findings are credible. To ensure that the research is needed and is relevant, the research question needs to be decided before the methodology is chosen.

Several researchers have advocated the use of participatory action research as being the most appropriate approach to use with mental health consumers. This involves the researcher working in a mutually agreed partnership with consumers, an ideal way of involving people with experiences of mental illness in the research process. Participatory action research may not be the best approach however, when the study is short term, involves groups with differing interests, has a non-negotiable aim, where there is no commitment to partnership between researchers and participants, or is not considered a priority by consumers.

Sampling Issues

High profile consumer groups or mental health services are an easily accessible and obvious solution to a researcher in need of a 'consumer perspective'. Care needs to be taken however, to ensure this easy accessibility does not compromise the selection of the most appropriate sample for the research. In the same way, research involving a sample of people with experiences of mental illness (unless it is a true random sample of an appropriate size) will not be generalisable to all consumers. Subsequent publicity of findings may contribute to inaccurate and misleading stereotypes unless the sampling criteria are mentioned.

Mental health professionals are sometimes asked to weed out from a research sample anyone who, in their opinion, should not be asked to participate (Warren and Allan 1997). At other times, mental health

professionals may be asked to decide who is well enough to participate. One justification for these approaches is to avoid further distressing consumers who are unwell by asking them to participate in research. However, the distress of not being asked when others have been also needs to be considered. Another point to consider is that if mental health professionals are able to decide who should, or should not participate in a research project, the project is open to accusations of sample bias (especially if the project is a service evaluation).

Finishing the Research

Ensuring that a summary of research findings is available to all participants if they would like it is one way of showing consumers what value their participation has added to the research process. Sometimes the publication of research can attract media attention and findings may be taken out of context and used to perpetuate stereotypes. If consumer groups also have copies of the summary or publication they can be prepared for any media interest, and can contribute to any debate.

There is no such thing as the perfect piece of research. Involvement of consumers at the end of the process, when the research is being evaluated, is as essential as it is throughout the rest of the process.

Some Questions to Ask During the Research Process

These questions are suggestions to act as a guide to encourage ethical and non-discriminatory research. There are no right or wrong answers - the aim is to make sure that thought is given to the particular areas and that active decisions are made. It is by no means an exhaustive list.

What is the purpose of the research? Does it need to happen? Can the answers be found without having to do new research? What are the benefits for consumers? Is it a priority for consumers? How are consumers involved? Are training and research support available to involved consumers?

Should ethical approval be sought?

Will the methodology used answer the research question? Does the methodology limit the application of the research? Would the methodology still be acceptable if the participants were not consumers?

Is the sample selection appropriate? Is there a danger of the participant population being over-researched?

How are potential participants to be approached? What is the consent process? Have all the potential risks and inducements to the participants been identified? What are the grounds for deciding someone may not be capable of providing informed consent? What happens if someone is not capable of providing informed consent?

What are the protocols to ensure that there are appropriate boundaries between service provision and research?

Is an assurance of anonymity possible? How will confidentiality be assured? How will the data be stored?

How will the data be analysed? Is the analysis of consumer responses given the same weight as other responses?

Will the participants be given a summary of the findings? How will the media interest be handled? Are the findings going to be distributed to consumer groups? Will the research process be evaluated and will consumers be involved in this?

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