MENTAL HEALTH RESEARCH: A PATH TO PERSONAL, INTERPERSONAL, AND POLITICAL CHANGE FOR PARTICIPANT RESEARCHERS?

PATRICIA A. ROBINSON

MENTAL HEALTH RESEARCH: A PATH TO PERSONAL, INTERPERSONAL, AND POLITICAL CHANGE FOR PARTICIPANT RESEARCHERS?

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Abstract

People who have mental illnesses often find themselves being spoken "about" or spoken "for" by others. In contrast, this study is about directly obtaining the views of individuals who have or have had mental illnesses and have participated in research in roles other than as research subjects. The purpose of the study is to determine whether or not they believed that their research experiences positively contributed to their personal, interpersonal, and political lives, a proposition often held by professionals in the literature. The study also sought to determine the factors that were associated with their reported outcomes and whether they endorsed more participatory models of research.

Multiple strategies were used to identify and recruit individuals that met the study criteria. Known consumer/survivor researchers were contacted directly, others were recruited through their attendance at conferences or through contact by other researchers. The study sample consisted primarily of white females over the age of 40, most of whom had post secondary degrees and who had had a variety of roles in their research experience.

Scales were created that measured the extent to which respondents believed that their research experiences were participatory; the changes they had experienced in their personal, interpersonal, and political lives; and the degree to which they endorsed participatory methods of research. Bivariate Correlations and one-way ANOVAs were computed to test the relationships

among the degree of "participatoriness" and respondent outcomes as well as the relationships between the participants' level of research experience, the research environment and their reported outcomes.

Respondents were generally positive about the degree to which their research experiences were participatory and indicated that they had experienced some changes as a result of their research experiences. Their outcomes were significantly, positively related to the extent to which they felt their experiences were participatory.

Social work research is fertile ground for participatory models of research, given the profession's commitment to the principles of social justice and empowerment. Social work education, particularly doctoral education, should expose students to these more inclusive research approaches and prepare them to engage in authentic participatory research models.

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CHAPTER ONE

INTRODUCTION

This study is about hearing the voices of individuals whose views are oftentimes unheard. People who have mental illnesses often find themselves being spoken "about" or spoken "for" by others. Typically, it is the professionals, whether clinicians or researchers, who dominate the discourse. In contrast, this study is about directly obtaining the views of individuals who have or have had mental illnesses and have participated in research in roles other than as research subjects. It is an effort to determine, from their points of view, whether or not they believed that their research experiences positively contributed to their personal, interpersonal, and political lives.

This first chapter presents an introduction and overview of the dissertation. The subject of the inquiry is introduced and its relevance to social work is discussed. The statement of the problem, the research questions to be addressed, and the importance of the study as well as the organization of the dissertation are also presented. However, before proceeding, it is important to comment about the language that is used in the following chapters.

Language and the use of specific terms in referring to people who have or have had mental illnesses is an important consideration in this dissertation. Recognizing that there is a lack of consensus about the appropriate or preferred term among individuals who have such disorders, the use of the term consumer/survivor is being employed in this document because of its use in

other work (Campbell, Ralph, and Glover, 1993; Nelson, Lord, and Ochocka, 2001; Tomes, 2006; Van Tosh, 1993). The use of the term is intended only for clarity to distinguish individuals who participate in research who have or have had mental illnesses from other professional researchers who are presumed not to have such disorders.

Participatory Research

Research has been defined as "a studious inquiry or examination, especially the investigation or experimentation aimed at the discovery and interpretation of facts, revision of accepted theories or laws in the light of new facts or practical application of such new or revised theories or laws" (Merriam-Webster's OnLine Dictionary, 2006). It is a process of knowledge development that is generally conducted by professionals trained in the practice, i.e., people who have been schooled in the requisite technologies for conducting research. Typically, the researcher (often influenced by the research agendas of funding sources) has identified the problems to be studied, determined the means and methods for conducting the inquiry, and decided to whom the results should be disseminated (Guba and Lincoln, 1989).

However, there is an alternative paradigm, one in which individuals who have had direct experience with the problem or matter to be studied participate in the research endeavor as colleagues rather than as subjects (Altpeter, Schopler, Galinsky, and Pennell, 1999; Evans and Fisher, 1999a; Evans and Fisher, 1999b; Guba and Lincoln, 1989; Hick, 1997; Rempfer and Knott, 2001; Sohng,

1992; Telford and Faulkner, 2004; Whyte, 1991). This participatory research model has emerged partly due to the pressures exerted by disadvantaged and marginalized groups who have heretofore only been the subjects of research and who have rarely benefited directly from the research outcomes. They have asserted their expectations that knowledge that is derived about them -- their experiences, as well as the systems that have an impact upon them -- be generated with their input. Their point is succinctly yet eloquently captured in the phrase, "Nothing about us, without us" (Charlton, 2000).

More recently, federal funding agencies in the United States have started to encourage, if not require, participatory forms of research (Green, 2003). The federal Substance Abuse and Mental Health Services Administration (SAMHSA), for example, is one agency that has issued funding opportunities in which they have required new grantees to demonstrate that they have included individuals who have experienced mental illnesses in the research process. Recently the National Institute of Mental Health (2006) issued a call for proposals that focused specifically on participatory methods of research. There are also a number of other public and private sources which now provide funding for community-based participatory research (Seifer, Kauper-Brown, and Robbins, 2004). The National Institute of Mental Health (1998) also requires that review groups reviewing proposed social services research include individuals who represent persons with mental illnesses.

Finally, researchers themselves have come to appreciate the unique contributions that individuals who have had direct experience with the problem under study are able to make to the research process. Participants have been able to provide valuable input in determining relevant research questions, appropriate research methodologies, and important dissemination audiences (Cleary, Walter, and Escott, 2006; Downey, East, and Manning, 2002; Faulkner and Thomas, 2002; Halliday, 2003).

In addition to the contributions that participants have made to the research process, the participatory research literature identifies the empowerment of participant researchers as an explicit goal of the practice (Dullea and Mullender, 1999; Evans and Fisher, 1999b; Wells et al., 2006). Although the meaning of the term empowerment has become ambiguous through its various uses, it provided an appropriate theoretical framework for this inquiry. Empowerment theory identifies both subjective and objective dimensions of change, i.e., people who are empowered develop a sense of self-efficacy and self-confidence, which ultimately leads them to take action to improve their situations (Robbins, Chatterjee, and Canda, 1998).

Participatory research models take various forms. The degree to which individuals participate may vary from minimal levels of involvement, such as serving as an occasional advisor or entering data, to high levels of engagement in which participants actually create the research agenda, direct and manage the research process, and determine the dissemination of results. Of primary interest

in this study were participatory research models that were used in mental health-related research that included individuals who currently or previously had mental illnesses because of their special perspectives as insiders. While their actual roles and levels of responsibilities may have varied in the research process, their contributions were informed by their personal experiences, and their views helped shape the research process in some way.

This investigator explored the concept of participatory research earlier in a series of focus groups conducted with researchers at the Louis de la Parte Florida Mental Health Institute (FMHI) at the University of South Florida (Robinson, 2003). FMHI is a university-based institute whose mission is to improve the lives of individuals with behavioral health disorders through programs of research and training. Institute faculty, representing a variety of disciplines including social work, are engaged in a wide-ranging portfolio of mental health-related research. In some instances, they had utilized participatory research methods by including family members of children with serious emotional disorders, as well as individuals who have mental illnesses in their research activities. However, participatory models were not the norm.

The purpose of the focus groups was to solicit the views of professionally trained researchers regarding the value and feasibility of using participatory research models within their own practice of mental health-related research. The focus group participants offered a number of strengths that characterize participatory methods. For example, they suggested that research was better

informed when individuals with direct experience with the issues under study were involved. By including individuals with mental illnesses as partners in the process, the FMHI researchers reported that the focus of the research was more likely to be relevant to the people who could be affected by the issues under study. Thus, the results were more likely to have utility for service providers as well as the people who obtain services. The views of the FMHI researchers were also supported by other researchers in the professional literature who identified many of the same benefits as a result of participant involvement (Altpeter et al. 1999; Jackson and Kassam, 1998; Linhorst and Eckert, 2002; Trivedi and Wykes, 2002).

Aside from benefiting the research process, the literature also suggests that participatory research benefits the individuals who participate as research colleagues. More specifically, it is reported that people who participate in the development of knowledge through research become empowered through the process; they gain new knowledge and skills, and they develop increased confidence and self-esteem (Evans and Fisher, 1999a; Evans and Fisher, 1999b; Faulkner and Thomas, 2002; Freire, 2000; Nelson, Ochocka, Griffin, & Lord, 1998; Salzer, 1997; Sohng, 1998). Presumably, they begin to place their own problems within a broader context and come to appreciate that many of their problems are not due to personal failings. Their newly developed skills, knowledge, and sense of self-efficacy can enable them to engage in social change.

Relevance to Social Work

Participatory models of research have particular relevance for the social work discipline because of the profession's emphasis on social justice, empowerment, and social change, values that are also characteristic of participatory research (Gutierrez, Parsons, & Cox, 1998; Lee, 1994; Simon, 1994). As social workers have come to understand the value of a person's participation in her/his treatment or services, they may appreciate the value of their inclusion in research as well (Hick, 1997). However, in conducting research within a participatory framework, social workers should understand the elements of the practice that are most conducive to achieving the goals of empowerment. They should also be aware of any adverse conditions that are likely to be detrimental in order to construct research processes that avoid harmful consequences. The findings from this study represent a step towards better understanding of the experiences of individuals, who have, or have had, mental illnesses and who have participated in research as well as the outcomes they have achieved.

The Problem

Just as researchers' assumptions regarding the scientific benefits of participatory research models should be examined and tested; there is also the need to explore the assumptions about the benefits of participation in research for participants. There is little indication in the literature that such assumptions have been systematically examined. In addition, much of the existing literature

regarding participatory research describes processes that have involved economically and politically oppressed individuals. There has been less discussion of the involvement of people with disabilities, e.g., mental illnesses, or the particular outcomes they may have experienced. This gap in knowledge obscures the fact that while people with disabilities may also be economically oppressed and politically disadvantaged, they often face discrimination as a result of pervasive disparaging views about their disabilities. People with disabilities also must contend with the manifestations of their disorders or illnesses, which are not always under their control and which may actually interfere with their involvement in many types of activities, including research.

There are few personal accounts by participants in the literature that describe their experiences in research activities and, when found, they often relate to their involvement in a specific project. Personal accounts by individuals who had a mental illness and who had been engaged in mental health-related research were even rarer (Morrell-Bellai and Boydell, 1994; Rose, 2003; Viney et al. 2004; Wykes, 2003). Apparently, participant views of their research experiences and the outcomes of their involvement are largely unexplored.

Study Goals

The purpose of this study was to explore the views of research participants regarding their experiences as colleagues in the research process. Rather than assume the oft-cited professional view that the outcomes of the participatory research process include the empowerment of the people involved,

this study sought responses from participants themselves about the changes they have experienced as a result of their research experiences. The study survey focused on the changes, if any, participants had experienced in their personal and interpersonal circumstances as a result of their involvement in research. In addition, participants were asked about the extent to which their research experiences enabled them to advocate for or to initiate changes in the social/political structures that affect them.

Individuals who self-identified as having a mental illness and who were known in the mental health research field were asked to participate in the study. They also were asked to invite other individuals who met the study criteria to offer their perspectives in order to gain a broader view of participant experiences. The specific questions explored through this inquiry were:

1. To what degree have participant researchers with mental illnesses (presently or in the past) felt they were meaningfully involved in the research process?
2. What factors contributed to their characterization of their experiences?
3. What is the relationship of participation in research to their personal, interpersonal, and political lives?
4. What are their views about the feasibility and utility of participatory research models?

Another important goal of the study was to obtain new understandings of participatory research methods and how they contribute to positive changes for

participant researchers. The outcomes of this study provide some insight into the practice of research when individuals with mental illnesses have been included in the process. If it can be assumed that the views of those who participated in the study are not that different from other consumer/survivor participant researchers, this study should inform the use of research models in which all individuals who participate benefit from the process while achieving better scientific practices.

Organization of the Dissertation

Chapter Two provides a review of the participatory research and empowerment literature as it pertains to the practice of research and the potential empowerment of participant researchers. The language and key concepts that are characteristic of the empowerment discourse and the participatory research paradigm are identified and defined.

Chapter Three describes the methods used to address the research questions. Included are descriptions of the overall study design, the study sample, sample recruitment strategies, the instrumentation, and the procedures used to collect the data as well as the methods of data analysis.

The fourth chapter presents the results of the data collection and analyses, including descriptive statistics for each variable as well as the constructed scales and the computed correlations among the variables of interest. The results are organized as responses to each of the four study questions.

Chapter Five briefly summarizes the study and includes a discussion of the study findings that pertain to the research questions. The study limitations are described along with suggestions for improving future studies. The implications of the study findings for social work practice are discussed and recommendations for future research are also presented.

CHAPTER TWO

Conceptual Definitions and Literature Review

There is growing interest in participatory forms of research, yet there is still much to be learned about what constitutes participatory research, how it is carried out, and the outcomes for individuals who participate in the practice. It is clear from the literature that there are many variations of the participatory research model, but there are also common features, which include the inclusion of individuals who would typically be "subjects" of the research and their achievement of life changes or empowerment through their participation in the process. This study is about the experiences of consumer/survivor participants in the research process and whether the claims made by professionals in the literature about the empowering potential of participatory research are confirmed by the participants themselves. In this chapter, the relationship between the practice of research and the potential empowerment of research participants is explored. The language and key concepts that characterize the participatory research paradigm and the empowerment discourse are identified and defined. Finally, the critical questions explored through this study are identified and discussed.

Participatory Research

Participatory Research Defined

Participatory research is a practice in which individuals, who have more often been the subjects of research, are involved in the generation of knowledge.

Typically, this form of research involves collaboration between professional researchers and individuals who may not be professionally trained as researchers yet have life experiences that provide them with practical expertise and an insider's view of the issues (Park, 1993; Rempfer and Knott, 2001; Whyte, 1991).

Unfortunately, there is little consensus in the literature about the preferred term for participatory research (Altpeter et al., 1999; Patton, 1997; Wortley, 2000; Minkler and Wallerstein, 2003). It is not uncommon to find terms such as participatory action research, action research, action inquiry, community-based participatory research, or collaborative action research used interchangeably to refer to a research process that encompasses the inclusion of individuals as partners in the research process. However, despite the lack of consistency regarding the terms, certain characteristics of participatory research are commonly described. Altpeter et al. (1999) identified several features of participatory research approaches that emerged in their review of the literature.

- It exposes and addresses social or practical problems with the goal of stimulating action for social change. Theory development is secondary and is grounded in action.
- It involves collaboration, cooperation and co-learning, co-researchers are established.

- It is a scientific method of investigation that promotes high validity because the participation of the community generates more accurate and authentic analysis of the participants' reality.
- It is a cyclical process, encompassing problem diagnosis and analysis (fact-finding), planning and implementation (action), and feedback (evaluation), followed by a new cycle. The community is actively engaged in the origination, definition, and analysis of the problem and the subsequent solutions.

Wells and colleagues (2006) have posited that community-based participatory research is not a single research model but rather is a philosophy or an orientation to research with a set of principles the guide methods. Participatory research models differ from the traditional research paradigms where the professional researcher develops and controls the knowledge derived from the process, and participants (the research subjects) often are not even aware of the research results.

The underpinnings of participatory research include a commitment to shared ownership of the research endeavor, including setting the research agenda and shared control of the process and outcomes (i.e., the collection of data and data analysis) as well as the dissemination of results (Danley and Ellison, 1999; McTaggart, 1997). There is a shared learning experience among all who are involved. Participants learn to define and critically analyze the problems, and the researcher gains insights that can make their research more

relevant. Unlike traditional research models, participatory research encourages activism and community-based and community-initiated action. Because the information gained from the research endeavor is owned and shared by all the participants, that information can empower individuals to take action (Sohng, 1992).

Participatory research models have been used in a variety of settings involving people who generally have been on the margins of knowledge discovery, if they are included at all. Hotel room cleaners (Lee, Krause, and Goetchius, 2003), transgendered individuals (Clements-Nolle and Bachrach, 2003), and Cambodian girls in California (Cheatheam and Shen, 2003) are a few examples of the diverse populations that have been engaged in participatory research projects. There is also evidence of its use involving people with disabilities, including individuals with psychiatric disorders (Carrick, Mitchell, and Lloyd, 2001; Fossey, 2002; Morrell-Bellai and Boydell, 1994). It is the involvement in research of people who have or have had psychiatric disorders, which is the specific focus of this study.

Historical Background

The term "action research" was first coined by Kurt Lewin in the 1940s as a way of referring to a different approach to problem solving. The expression was intended to capture an iterative process of planning, action, and the analysis of the results (Wallerstein and Duran, 2003). Participatory research models emerged during the 1970s in developing countries struggling with serious social,

economical, and environmental problems (Hick, 1997, Tandon, 1996). When it became clear that mainstream economic and development projects were failing to reduce poverty and inequality, researchers began to develop alternative approaches that increased the participation of the poor (Borgatta and Borgatta, 1992). Participatory research gained prominence at the World Symposium on Action-Research and Scientific Analysis in Cartegena, Colombia in 1977. Subsequent writings "helped sharpen the conceptions and aims of participatory research and exposed it to the wider research community" (Hick, 1997, p.67).

Participatory research has been associated with Paulo Friere's views expressed in his book Pedagogy of the Oppressed. Borgatta and Borgatta (1992) succinctly summarized Friere's position on education and investigation as the following:

> Teaching and research should not be dominated by experts but should be based upon dialogue with a community of oppressed people. Through dialogue and collective action, people can develop critical consciousness, learn the skills they need to improve their situation and liberate themselves (p. 1429).

More to the point of participatory research, "...the methodology proposed requires that the investigators and the people (who would normally be considered objects of that investigation) should act as *co-investigators*" (Friere, 2000, p.87).

Participatory research was fostered by challenges to positivist social science by feminists, Marxists, critical theorists, and others who emphasized the links between knowledge and power. Critics of positivist methods proposed alternative paradigms that brought theory and research together with political

action and gave the people being studied more power over the research. "The development of these alternative paradigms, together with the emergence of participatory research in the Third World and political activism accompanying social movements of the 1960s and 1970s sparked research projects by North American social scientists" (Borgatta and Borgatta, 1992, p.1429).

Benefits

There has been growing interest in participatory research methods as many researchers have come to appreciate the contributions made to the research process by individuals who have had direct experience with the issues being studied (Cleary, Walter, and Escott, 2006; Faulkner and Thomas, 2002; Halliday, 2003; Jackson and Kassam, 1998; Minkler and Wallerstein, 2003). For the researcher, the involvement of people affected by the issues helps to make the research more relevant. It brings an insiders' view to the questions being asked and helps to make the research outcomes more salient (Linhorst and Eckert, 2002; Rempfer and Knott, 2001; Rogers and Palmer-Erbs, 1994; White, Nary, and Froelich, 2001). People who have traditionally been the subjects of research also have come to appreciate the contributions they can make to the research process (Griffiths, Jorm, and Christensen, 2004; Hanley, 2005; Minogue, Boness, Brown, and Girdlestone, 2003; Reeve, Cornell, D'costa, Janzen, and Ochocka, 2002). For the participant, access to the research process represents an opportunity to help shape the research agenda, making it more likely that the issues and problems that are most important to them will be

studied. Through their involvement they may also have influence over the way the research is conducted and have access to the information derived from the process. However, these aspects of the participatory process may have only indirect benefit for the participant. There are other outcomes that have been identified with participation in research that may affect the participant more directly, such as the acquisition of new skills and knowledge, increased self-esteem, and confidence in their ability to create change--outcomes which are often associated with the construct of empowerment (Fossey, Epstein, Findlay, Plant, and Harvey, 2002; Morrell-Bellai and Boydell,1994; Ramon, Castillo, and Morant, 2001; Salzer, 1997, Telford and Faulkner, 2004).

Participation

Despite the ambiguity in the terminology of participatory research, one key element found to be consistent among various forms of participatory research is *participation* on the part of individuals with an insider's view. Because participation is a key concept in the participatory research process, it bears further examination.

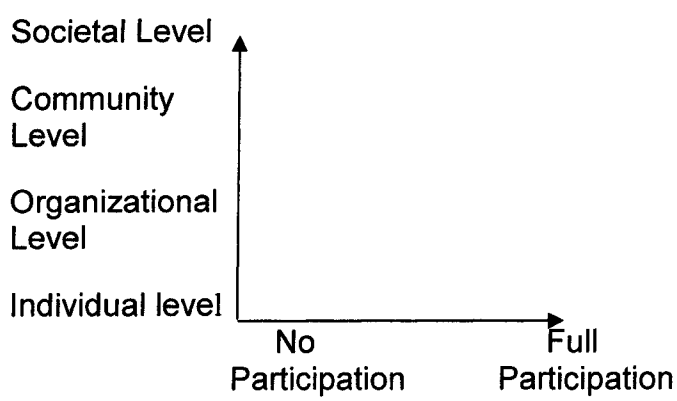
The dictionary defines participation as "to take part or have a share in something" (Merriam-Webster OnLine Dictionary, 2006) The construct of participation is rooted in the belief, dating back to the Age of Enlightenment, that people have innate abilities to reason and determine their own actions (Freeberg, 1989). In the United States, the notion of participation is highly consistent with the democratic principles of government and was formalized by the passage of

participatory policies within federal legislation (for example in the amendments to the Social Security and Equal Opportunity Acts) which have further fostered citizen participation in the United States. At the same time, minorities, women and other marginalized people asserted their rights to inclusion through the various civil rights and women's movements in the U. S. (Gamble & Weil, 1995; McAllister and Walsh, 2004). In mental health, two trends prompted a change in attitudes towards consumer/survivor involvement: 1) the emergence of self-help groups and larger consumer umbrella organizations and; 2) an emphasis on consumer/survivor involvement incorporated into federal and state policy (Breakey, et al, 1996, p.167).

Participation can be conceptualized as a multidimensional construct in that it can refer to participation at the individual, organizational, community, or societal levels and can range from little or no participation to full integration and/or control, as illustrated by the following figure.

Figure 2.1

The Multiple Dimensions of Participation



Within a mental health context at the individual level, a person may have no involvement in decisions that affect them personally, such as in involuntary treatment or when a guardian has assumed decision-making power on their behalf. At the other end of the continuum, full participation at the individual level assumes that the person is fully capable of and is wholly engaged in making decisions that affect him or her. Self-help services, such as community-based mental health drop-in centers or respite programs where individuals are in charge of their own recovery, might exemplify the other extreme. Similarly, at the organizational level, a person may have no voice in organizational policies or practices that could ultimately affect her/him. Decisions made by a governing board of a community mental health center that has no consumer/survivor representation is one example of the lack of participation at the organizational level. At the other end of the participation continuum, a person would have access to and influence in organizational decision making by either having membership in the organization's governing board or through an advisory council.

Participation at the community and societal levels also ranges from no involvement in decision making to full engagement. For example, people who are removed from the community by being committed to a state hospital or incarcerated represent individuals at the "no participation" end of the continuum, while individuals who are members of decision-making boards or are in positions

of influence, such as in statewide advocacy or lobbying groups, represent the full participation end of the continuum.

Participation in Research

Within the context of research, participation can take many forms. Hick (1997) offers a useful framework for the discussion of the variations or degrees of participation in the participatory research process. He proposes that participation can be conceptualized along two dimensions. The first dimension is that of control over the research process. Direct control on the part of the participants means that they are in charge of the research activities and control the direction of the research. Less or indirect control means that there are intervening persons, conditions, or agencies that affect the research on behalf of the participants.

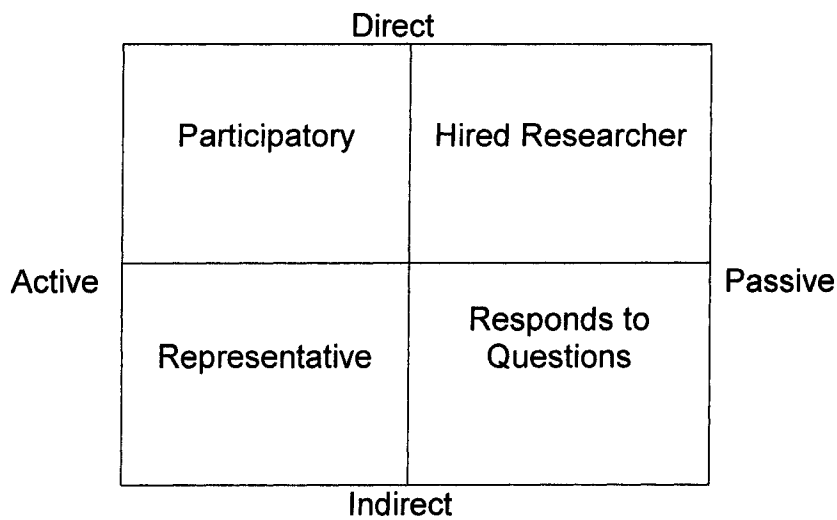
The second dimension is related to the amount of actual involvement that participants have in the process. Hick (1997) considers participants to be active in the process if they are actually conducting research activities, collecting and analyzing data, and writing the research reports. According to Hick, the ideal participatory model that offers the greatest potential for empowerment is when the participant has the most direct control over the process and is actively involved in actual research activities (the upper left quadrant in the figure below). The researcher plays a catalytic role and does not dominate the process. The least participatory model, which is typical of traditional research, is where the participant has no control over the research process and is not involved in the

research activities (the lower right quadrant). The researcher conceptualizes the research problem, designs, collects, and analyzes the data from subjects, writes the research report, and disseminates the findings (Hick, 1997).

Figure 2.2 developed by Hick (1997) represents the various ways in which individuals are involved with the research and the degree to which they control the process.

Figure 2.2

Characteristics of Participation in Research



From this perspective, it is apparent that participants' roles and their degree of control over the process can vary significantly. Another way of illustrating the point is to consider an individual's degree of participation upon a simple continuum from no or minimal involvement (as when they are only the subjects of research) to full participation in the research process (as a principal investigators or research directors), as indicated below.

Research Subject ←——————————→ Principal Investigator/director

At one end of the continuum, participants would not be a part of the research process and would serve primarily as the subjects of the inquiry, such as respondents to a survey or participants in a drug study. At the other extreme, participants would control the research agenda and the process, determine the research design, and be involved in carrying out the research functions. The participants would also control the dissemination of findings. This continuum was more fully described by Minogue et al. (2003) as consisting of five levels of participation: 1) consultation; 2) collaboration; 3) user-commissioned; 4) user-controlled or led; and 5) user-disseminated. The degree to which participants are involved in the process is part of what differentiates participatory research practices from more traditional research approaches.

While participation is obviously key to the participatory process, what constitutes participation (i.e. authentic participation) from the participant's view may be very different from the way it is conceptualized by the professional researcher. For example, in an earlier review of the literature on the subject of participation (Robinson, 2000), it was found that professionals talked about participation more often in terms of the mechanics of the process (e.g., the time it takes to involve participants or the resources needed to make participation possible) than the interpersonal aspects of the endeavor.

In contrast, participants emphasized the personal aspects of participation. They talked about trust, self-esteem, feeling safe, being listened to, and having their experiences validated. They spoke of being treated as colleagues and described the burden of self-disclosure (of their mental Illnesses) and the discrimination they sometimes faced as a result of sharing their experiences. For them, participation was about the interpersonal relationships with researchers. As one participant noted, "We speak in the first person, not the academic third person. We give ourselves along with our knowledge." (White,1989, p. 3). Consequently, the degree to which consumer/survivors view their experiences as participatory may have more to do with the socio-emotional aspects of their involvement than with their specific functional role or the extent of their responsibilities in the research process.

The Research to Power Model

If, as has been posited in the literature, participation in research is empowering, there must be relationships between research and the generation of knowledge, as well as between the generation of knowledge and the outcome of empowerment. The proposition that research produces knowledge of various types, and that by acquiring knowledge through participation in the process a person also acquires power, can be represented simply as follows:

Research $\longrightarrow$ Knowledge $\longrightarrow$ Power

The argument that through acquiring knowledge, a person acquires power is a position broadly held in the literature (Connor, 1999; Foster-Fishman, Nowell,

Deacon, Nievar, and McCann, 2005; Gaventa and Cornwall, 2001; Park, 2001; Yeich and Levine, 1992). The often-cited proposition that an individual is *empowered* through his or her participation in the generation of knowledge appears to be predicated upon the premise that their knowledge and critical analysis of the structures and circumstances that affect them in some way facilitates their having the power to change those factors and environments. As noted by Hall (2001), "The process of participatory research can create a greater awareness in the people of their own resources and mobilize them for self-reliant development." (p.173) If research is a way of acquiring knowledge, then participation in research should be a means by which individuals are empowered to create change. However, this assertion, most often posited by professionals, remains to be confirmed by participant researchers themselves.

In order to establish a common frame of reference for the discussion of outcomes derived by consumer/survivor researchers in the research process, the concepts that make up the research-knowledge-power model are defined as follows.

Research

The first key concept is research and what constitutes research. A common definition is a "studious inquiry or examination, investigation, or experimentation..." (Merriam-Webster Online Dictionary, 2006) which implies a formal course of inquiry. In Coryn's (n.d.) discussion of research, it is noted that there are "competing definitions of the term and little apparent consensus" about

what is and what is not, research. However, the author offers that "research is a truth-seeking activity which contributes to knowledge, aimed at describing or explaining the world, conducted and governed by those with a high level of proficiency or expertise" (p.1). This latter assertion, i.e., that research is conducted and governed by those with a high level of proficiency or expertise, supports a more traditional view that research requires more formalized approaches that employ rigorous scientific methods and that these approaches are more privileged than others. The assumption is that such methods produce the most authentic and reliable information and provide the greatest potential for understanding and explanation. However, as a process of discovery, research may not always be so formalized; there may be other forms of research that yield information and produce knowledge.

Distinctions are often made between basic and applied research. Basic research is typically undertaken to acquire new knowledge without a specific application, whereas the goal of applied research is to determine possible uses for the findings or to find new ways of achieving some specific and predetermined objective (Coryn, n.d.). The nature of participatory research, with its emphasis on problem solving in a real world context, would clearly be consistent with the definition of applied research. However, as Coryn (n.d.) points out, "the need for the distinction is questionable since both applied and basic research contribute to knowledge" (p.1). It is the contribution to knowledge that is fundamental to the research-knowledge-empowerment model.

Knowledge

Knowledge has been commonly defined as "the fact or condition of knowing something with familiarity gained through experience or association" (Merriam-Webster Online Dictionary, 2006). Rather than engage in the epistemological debates that have surrounded the questions of what constitutes knowledge, how it is acquired and what people know, the most salient point to be made about knowledge that is relevant to participatory research is that experiential knowledge is considered a legitimate form of knowing.

Park (2001) posits that there are various forms of knowledge to be considered within the participatory research framework. He argues that the views of knowledge--as expressed in many of the discussions of participatory research that equate knowing with describing, explaining, or understanding a phenomena as an object (what he refers to objective knowledge)-- are limited (p.82). He suggests three finer distinctions in the types of knowledge that are involved in participatory research. He identifies representational knowledge (both functional and interpretive), relational knowledge, and reflective knowledge as having important roles within participatory research.

The functional subtype portrays the relationships between variables as one being a function of the other, as in causal or correlational relationships. Knowledge of these relationships enables predictions and, at least theoretically, the ability to control events. He describes the interpretive subtype as the "...understanding of meaning and that requires that the knower come as close to

the to-be-known as possible. It requires taking into account the backgrounds, intentions and feelings involved both in understanding human affairs and textual and other kinds of artifacts that are human creations" (p. 83). Relational knowledge has potential for bringing people together affectively as well as cognitively and is what helps make community possible in participatory research. Reflective knowledge involves participants critically analyzing and evaluating questions of morality and values related to their life conditions and the proper actions to take.

"If the goal of participatory research is the production of knowledge, we cannot understand knowledge in terms of a narrow definition of rationality that recognizes only the technical." (Park, 2001, p. 88). What Park is suggesting is that there are different forms of knowledge that are derived from the complex experience of participatory research and that each knowledge form contributes to a different aspect of power. Representational knowledge provides the cognitive basis for building competence needed for controlling the world. Relational knowledge translates to the power of solidarity, i.e., participants are sustained by seeing themselves as a part of a larger whole. Reflective knowledge builds the power to critically evaluate one's life conditions and provides self-confidence to engage in social change (p. 87).

Park's disaggregation of knowledge facilitates a better understanding of the relationship between knowledge and power within the participatory research discussion. However, the question of how participants view the knowledge they

have acquired through participatory research and its role in empowering them to make changes in their personal, social, and political lives remains to be explored.

Power

The third key component of the research-knowledge-power model is the complex concept of power. Power can be expressed in many forms and conceptually is often fraught with political overtones. A common definition of power that is most relevant for purposes of this discussion is that it is "a possession of control, authority, or influence over others" or "an ability to act or to produce an effect" (Merriam-Webster Online Dictionary, 2006).

Hollander and Offerman (1990) offer a useful typology of power in their discussion of organizations where they distinguish three types of power. The first refers to "*power to*" as "the opportunity to act more freely within some realms." The second is "*power over,*" which implies "explicit or implicit dominance" and the third is "*power from,*" the ability to resist the power of others.

Salzer (1997) in his discussion of consumer/survivor empowerment, further adds that the "*power to* form represents access to resources and participation in decision-making." *Power over* implies control over resources, whereas *power from* implies unrestrained ability to maintain dignity and integrity (p. 427).

The concept of power in the research-knowledge-power model is related potentially to all three forms of power. For example, knowledge gained from research may empower the individual to participate in decision making because

the person may have gained information acquired through the research process that is relevant to decisions to be made. The information acquired from research may also give the participant researcher decision-making power over how the research results are to be used. Also, depending upon the type of knowledge derived from the research, the participant may have information that will facilitate his/her control over events or circumstances. Finally, the knowledge and skills gained from the research process itself can provide the researcher with a sense of enhanced competency and improved self-esteem, which may make them less vulnerable to domination or control by others (Morrell-Bellai and Boydell, 1994; Ochocka, Janzen, and Nelson, 2002).

Empowerment

While the term "empowerment" is not part of the model under discussion, its meaning is derived from the root word "power," and it is the term most often associated with the outcomes experienced by consumer/survivors as a result of their research experiences. Specifically, empowerment is the personal outcome described in the literature as the by-product of knowledge acquisition (Beresford and Evans, 1999a; Evans and Fisher, 1999b; Hick, 1997; Sohng, 1992, 1998).

However, like many other terms in this discussion, empowerment is a term that has been used in so many different contexts that its meaning has become diffuse and ambiguous (Rogers, Chamberlin, Ellison, and Crean, 1999; Zippay, 1995). As a prominent mental health advocate once pointed out, "The more such a word is used, the less it is truly understood" (Harp, 1994, p. 84).

A common definition of empowerment is "to give official authority or legal power to or to promote the self-actualization or influence of" (Merriam-Webster Online Dictionary, 2006). Empowerment also has been defined as the process of helping individuals, families, groups, and communities to increase their personal, interpersonal, socioeconomic, and political strength and to develop influence toward improving their circumstances (Barker, 1995).

To better understand what constitutes empowerment within a mental health context, Rogers and colleagues (1999) collaborated with a research advisory board comprised of individuals considered leaders in the consumer/survivor movement to identify attributes of empowerment as defined by people who use mental health services. The board identified the following 15 items:

- Having decision making power
- Having access to information and resources
- Having a range of options from which to make choices
- Assertiveness
- A feeling that one can make a difference (being hopeful)
- Learning to think critically; learning to redefine who one is and what one can do; learning to redefine one's relationship to institutionalized power
- Learning about and expressing anger
- Feeling part of a group, not feeling alone
- Understanding that one has rights
- Effecting change in one's life and one's community
- Learning skills that one defines as important

- Changing others' perceptions of one's competency and capacity to act
- Coming out of the closet
- Growth and change that is never-ending and self-initiating
- Increasing one's positive self-image and overcoming stigma

This long list of attributes is consistent with the numerous definitions of empowerment found in the literature. The more commonly identified key elements include: having a sense of control over one's life and the things that affect the individual; enhanced self-esteem and a sense of self-efficacy; inclusion and participation; skill development and capacity for critical analysis; and access to resources and information, (Nelson, Lord, and Ochocka, 2001; Staples, 1990).

Miley and Dubois (1999) describe empowerment as both a process and an outcome. As a process, empowerment implies exercising psychological control over personal affairs, as well as exerting influence over the course of events in the socio-political arena. As an outcome, empowerment defines the end-state of achieving either personal or political power (p. 27). Julian Rappaport (1987), speaking from the perspective of community psychology, posits that "empowerment is not only an individual psychological construct, it is also organizational, political, sociological, economic and spiritual." (p. 131).

Returning to the model introduced earlier, if it can be assumed that knowledge is power, as Freire (2000) and others would suggest, then the process of knowledge discovery should facilitate the acquisition of power. It would follow logically that whoever controls the development of information would hold significant power. Thus it could be argued that research is a potential venue

for the empowerment of participant researchers. In particular, participatory models of research, where the emphasis is on co-learning and the sharing of power, may offer the best opportunity for empowerment of participants. At a minimum, the features of participatory research are highly consistent with elements of empowerment, as noted in Table 2.1.

Table 2.1

Comparison of Empowerment and Participatory Research

Elements of Empowerment	Elements of Participatory Research
Self-determination, self-efficacy, belief in self-worth, having control	Shared Decision-making
Having respect, being heard	Mutual respect, listening to each other
Access to resources	Remuneration for work, equal access to project resources, equipment
Community – belonging to something	Relationships are key among researchers Researchers acting as a team • sharing personal lives/stories • empathy/accommodation • sharing power
Critical thinking • Comes from education, information and resources • Enhances becoming "public" about illness	Research • is a critical examination of facts • increases critical thinking skills • develops new knowledge/insights Experiences of the individual are valued and validated
Action Can take action on their behalf or to join with others to influence internal and external structures	Action Research directed towards action, social improvements

While these arguments appear plausible, they need to be tested. One important source of verification is participant researchers themselves. There is

little evidence of *their* views regarding their experiences in research and whether those experiences have proven to benefit them in ways that are often described as empowering. Their views may or may not confirm the opinions of others (most often professionals) regarding the outcomes they achieved that were associated with their participation in research.

Also, there may be specific elements of the research experience, as viewed by participants that are more or less conducive to the proposed outcome of empowerment. For example, as suggested earlier, the interpersonal aspects of the experience may figure prominently in achieving empowerment from the participants' perspectives. There are likely to be other conditions or variables in the process that influence the personal, social, and political outcomes for the participant, but without seeking their views of the process, only the professional discourse will stand.

It was the purpose of this study to obtain the views of participant researchers, specifically participant researchers who have or have had mental illnesses and have participated in research, about their experiences in the research process and the outcomes they achieved as a result of their involvement. The following questions guided the inquiry.

1. To what degree have participant researchers who (presently or in the past) had a mental illness felt they were meaningfully involved in the research process?
2. What factors contributed to their characterization of their experiences?

3. What is the relationship of participation in research to their personal, interpersonal, and political lives?
4. What are their views about the feasibility and utility of participatory research models?

Without posing a formal hypothesis or an a priori theory about the factors that would contribute to the consumer/survivors' research experience and their outcomes, there were working assumptions that guided the exploration of the data. For example, intuitively it seemed logical that the person's level of formal education and the extent of his/her research experience might be associated with the degree to which they were integrated as co-researchers in the research process, i.e., the more professionally prepared, experienced researchers would be more involved in the research process. Participant researchers' perspectives about their role in the research process or the degree to which they felt accepted as research colleagues might also be associated with the outcomes they experienced and their views of participatory models of research in general. Specifically, the more positively they viewed their experiences, the more positive their outcomes would be and the more likely they would be to endorse participatory research. Finally, rather than an assumption, there was also a question about how the research environment (e.g., the funding source or host organization) might relate to participant researchers' characterizations of their research experiences.

Implications for Social Work Research

One form of social work practice is research (Atkinson, 2005). As social workers engage in research, they have the opportunity to potentially accomplish more than developing knowledge. Through the use of participatory forms of research, social workers can put their values of social justice, empowerment, and social change into practice. Participatory models of research that emphasize authentic participation and collaboration, shared decision making, and action-oriented outcomes are highly congruent with the social work values as noted in the following table that compares elements that are characteristic of participatory research models with the values/ ethics of the social work tradition.

Table 2.2

Comparison of Participatory Research and Social Work Values

Participatory Research Models	Social Work Values/Ethics
Researcher/participants collaboratively identify the research question or problem to be solved	Constructing collaborative partnerships with individuals Recognizing individuals as active subjects with interrelated rights, responsibilities, needs and claims Facilitating capacity and sharing power
Researcher and participants jointly develop methods using strengths of both the trained professional (skills, technical knowledge) and insiders views (derived from world experience)	Directing professional energies toward historically disempowered groups Emphasizing capacities of individuals rather than their incapacities
Researcher and participants collect data and jointly interpret meaning	Valuing human experience Appreciating the "many ways of knowing"

Table 2.2 Continued

Comparison of Participatory Research and Social Work Values

Participatory Research Models	Social Work Values/Ethics
Researcher and participants have equal access to results and collaboratively determine use of information	Valuing self-determination
Researcher and participants benefit from research experience • New knowledge/skills that generalize • Knowledge to create change • Empowerment	Valuing the empowerment of individuals Working towards social justice.

There are challenges, however, inherent in the participatory process. Social workers have wielded a certain amount of control and power derived from their expertise and the fact that much of their practice has been with people on the margins of society who have been *powerless*. Sharing power is fundamental in participatory research models, but the traditionally dominant role played by the expert researcher is not always easily relinquished. To the extent that social work researchers are trained in traditional research paradigms, they too will be challenged by the need for power sharing in participatory models.

If social work research is about improving practice and stimulating social change, then the agenda of participatory research should support those outcomes. However, the research agenda is often established by the funding available from traditional sources, such as government agencies, that are sometimes viewed as part of the problem. Social workers engaged in research will be confronted with having to balance the need to secure resources for

research investigations while still focusing on the issues and problems that ultimately will make a difference in the lives of people being served.

Finally, the question of who benefits from the research endeavor is of concern. While there is evidence supporting the belief that participatory research models empower participants as well as enhancing the 'science,' there is less evidence of what participants themselves believe they have experienced from the process (Morrell-Bellai and Boydell, 1994; Wykes, 2003). Their views will determine if participation in research is, in fact, a path to empowerment.

CHAPTER THREE

METHODS

This chapter presents the methods used to address the research questions for this study. It includes a description of the sample of individuals from whom survey responses were sought, the methods for recruiting the sample, a description of the participation of the consumer consultants who were engaged to provide input to the study, the survey instrument used and how it was developed, the data collection procedures, and the methods of data analysis.

Purpose of the Study

This was an exploratory study designed to address a number of questions regarding the experiences of individuals who have mental illnesses and who have also been involved in research activities as participant researchers. As noted in earlier chapters, it has been suggested in the literature that individuals diagnosed with mental illnesses and who have participated in research projects in roles other than as respondents or subjects, have been empowered through the process (Foster-Fishman, Nowell, Deacon, Nievar, and McCann, 2005; Sohng, 1998). The assumptions underlying this premise are that by engaging in research, individuals acquire new knowledge and skills, they gain new confidence in their abilities, and as a result they assert more control over their lives. They may see their circumstances in the context of social and political structures and are mobilized to make changes in those structures that have traditionally oppressed or marginalized them. These assumptions, however, are

largely untested. The purpose of this study was to seek the perspectives of participant researchers in order to determine if they believe that they have benefited from their experiences as researchers in the ways postulated by others. While there were a few anecdotal accounts available in the literature that suggested that individuals do, indeed, benefit from their research experiences, there did not appear to be any systematic, empirical studies to confirm these views or to determine if they are commonly held among participant researchers.

The specific questions that were explored through this inquiry were:

1. To what degree have participant researchers who have mental illnesses (currently or in the past) felt they were meaningfully involved in the research process?
2. What factors contributed to their characterization of their experiences?
3. What is the relationship between participation in research and their personal, interpersonal, and political lives?
4. What are their views about the feasibility and utility of participatory research models?

Overall Study Design

This study used a mixed-method, cross-sectional survey approach. It was primarily a quantitative study that included the collection of responses to written, structured survey questions as well as qualitative comments in response to two open-ended questions. This quantitative approach provided a broader

representation of perspectives from a wider sample of individuals than would have been possible through a more qualitative method.

To complement the quantitative approach, four individuals who had experience in conducting research and have had personal experience with a mental illness were asked to provide consultation to the investigator regarding study sample identification, instrumentation, and data analysis.

The study questionnaire was designed to be mailed or e-mailed to potential respondents with cover letters explaining the survey and containing the essential elements of informed consent. An electronic, Web-based version of the survey was also created and made available for individuals who preferred to complete the survey online. Individuals were not paid to participate in the study but were given the opportunity to have their survey included in a random drawing for a $250 donation to be made to a charity, cause, or non-profit organization of their choice.

Study Setting

This study included individuals primarily in the United States who have had a personal experience with a mental illness and who have participated in research activities in some capacity other than as a respondent. While the focus was mainly on U.S. participant researchers, there was no way to control who might have received the survey, given that a snowball sampling approach was used where individuals were asked to forward the cover letter and survey to others that they might know who would qualify for inclusion in the study. For

example, one individual from Ireland contacted the investigator, requesting that a copy of the survey be mailed to her. Postmarks on returned envelopes indicated that some respondents were also from Canada. Targeted recruitment occurred mainly in the United States.

Study Population

This study sought to reach English speaking male and female adults (over the age of 21) who have, or have had, some form of mental illness (broadly defined) and who have participated in mental health related-research activities. There were no a priori specifications for the type or extent of the person's mental illness that would either qualify or disqualify them for the study sample. The definition of mental illness was self-determined by each respondent. That is, if after reading the introductory materials for the study they responded affirmatively to the first item of the questionnaire, they were included in the study. Thus, the sample likely included people with varying types and severity of mental disorders. Their experience with the illness may have been recent or in the past. They may still consider themselves as having a mental disorder and may or may not be experiencing symptoms of their illness, or they may no longer see themselves as having a mental illness. Individuals of all racial and ethnic backgrounds were eligible for inclusion in the study.

Respondents' roles in the research activities also may have varied from minimal involvement, such as serving on advisory committees or as consultants, to actually directing the research, but the study design excluded individuals who

had served only as respondents or "subjects" for research studies. There were no a priori requirements with respect to respondents' education levels or research experience in order to be included in the sample. Also, there were no pre-established criteria regarding the types of research in which respondents had been involved.

The primary reason for establishing such broad inclusion criteria was to allow for as many consumer/survivor researchers to participate in the study as possible. Employing more rigorous definitions might have unduly restricted the number of potential respondents.

Study Consultants

The four individuals who were asked to serve as consultants to this project were known nationally in the mental health field to have been involved in mental health related research in some capacity and had self-disclosed that they had (or previously had) a mental illness. Three were known personally by the investigator and were selected because of their accessibility, their national standing in the mental health field, and their experience. Two of them had recently participated in a national research project regarding consumer-operated services funded by the federal Substance Abuse and Mental Health Services Administration (SAMHSA), and the third person had participated in various roles in research projects conducted at FMHI at the University of South Florida. The fourth person had recently retired as a researcher from the University of Southern Maine.

Each person was contacted via e-mail with the initial request to provide consultation to the study and later contacted by phone to confirm their interest and willingness to be involved. They were also sent a formal letter that outlined the study along with a consent form that detailed the elements of informed consent. (See Appendix A) In addition to consulting with the investigator regarding protocol development, sample recruitment, and data analysis and interpretation, the consultants were asked to journal their experiences, thoughts, and feelings about being involved in this particular study. Each was sent a journal in which to record their notes in whatever manner they chose.

Each person agreed to participate voluntarily without compensation for their time. However, at the beginning of the study one of the consultants withdrew from participation due to other pressing priorities. At the end of the study, each consultant received a token of appreciation for having participated.

Sample Recruitment

Sample identification and the recruitment of respondents were the most challenging aspects of this study. Because there was no known registry of participant researchers who have experienced a mental illness, and there was no way of knowing how many such individuals existed, it was necessary to use a variety of methods and sources to reach persons who met the study criteria. As a consequence, data were collected over a protracted period of time using a variety of recruitment strategies.

Recruitment Strategies

Initially, the literature was used to find the names of published researchers who have disclosed their personal history of having a mental illness and for whom contact information was available. Typically, these individuals were well known in the mental health field as researchers. They had presented at conferences and participated in government-funded research activities as well as having published in the professional literature. Relevant mental health research conference attendee listings were also reviewed for names of individuals who identified themselves as mental health consumers or as representing organizations that might have involved consumers as researchers. As a result, the names of 30 individuals and their contact information were included in the first mail list.

Another means of locating potential respondents involved attending and distributing the cover letter of explanation and the survey at appropriate conferences and meetings. Information about the study and the survey was provided on a "take one" table in the exhibit area at the National Association of State Mental Health Program Directors National Research Institute (NRI) annual meeting, a national mental health research conference often attended by mental health consumer/survivor researchers. By conference end, 22 surveys with cover letters were taken from the table; however, there was no way of knowing who had taken them.

Information about the study and how to contact the investigator was also posted at the registration table for the National Alternatives Conference, a national conference organized and conducted by, and for, mental health consumers. A number of nationally known consumer researchers attended the conference and helped to facilitate efforts to contact other researchers who were in attendance. Additionally, information regarding the study was also provided whenever the opportunity arose, such as at the end of small workshops and to tablemates during meals. Ten cover letters and surveys were distributed directly to individuals at that conference.

Additionally, information about the study was presented at a retreat held by Florida's Peer Network. The Peer Network is comprised of individuals who have self-disclosed their mental illnesses and who are assuming leadership in helping others in Florida to have a greater voice in policies and practices that affect them. There were fewer than 30 participants attending the retreat, however, some of the attendees were known to be consumer/survivor researchers. Four individuals took surveys to complete, one of whom preferred to complete it in person at the meeting.

Because of their experience in research activities, the consultants to this study also were asked to contact individuals known to them about participating in the project and provide them with the investigator's contact information (including phone, mail and e-mail address). Similarly, professional researchers across the United States who were known to have involved consumers in their research

projects were also contacted, primarily by e-mail, and asked to either distribute the cover letter of explanation and the survey to others whom they knew and who might meet the study criteria or to provide them the investigator's contact information.

Posting of a cover letter and survey was also made on a Web-based listserv for community-based participatory researchers sponsored by the University of Washington in Washington State. From that posting, a research investigator using participatory research methods involving individuals with depression reported that they had distributed the cover letter and survey to their participants. Other listserv members also provided other leads for potential contacts. Each suggestion was followed up with an e-mail contact. Information was also provided to Consumer Quality Initiatives, a Massachusetts-based organization of mental health consumer/survivor researchers about their participation in the survey.

Recruitment Letters/E-mails

All the cover letters/e-mails that accompanied the survey contained the following elements:

- An introduction of the investigator
- A description of the individuals who were being asked to participate (i.e., individuals who have or have had a mental illness and have participated in research in some way other than as a respondent or subject)

- A description of the purpose of the survey, including the research questions
- A link to a Web-based version of the survey in the event respondents preferred to complete the survey online
- Indications of the approval of the Interdisciplinary Committee on Ethics in Human Research at Memorial University as well as assurances regarding confidentiality, the voluntary nature of their participation, their right to withdraw without adverse consequence, and contact information for the investigator, the Ethics Committee, and the investigator's supervising professor at Memorial University
- The offer to have their survey entered into a drawing for a $250 donation to be given to a charity, cause, or non-profit organization of their choice

Specific letters and e-mails were each designed to reach targeted individuals. For example, individuals known to be participant researchers received a letter acknowledging them as mental health researchers and inviting them to complete the survey in order to share their experiences and their views about participatory methods of research. (See Appendix B)

Individuals whose names were obtained from a research conference list of participants received a cover letter or e-mail that indicated that their name had been included in a list of conference participants. (See Appendix C) Individuals who received a letter or e-mail that had been passed on to them by a colleague

received a letter/e-mail indicating that one of their colleagues believed that they might be interested in participating in the survey. They were also advised that they were under no obligation to reveal to the person from whom they received the cover letter and survey whether or not they had participated in the survey. (See Appendix D) Cover letters with surveys that were left at "take one" tables at conferences were less personalized but included all the elements noted above.

Because this study sought to obtain the views of a narrowly defined population, i.e., individuals who have participated in research and who also have experienced a mental illness, and because of the need to protect the confidentiality of individuals who might meet the study criteria, it was necessary to use this multi-method approach to recruit respondents. Recruitment was further complicated by oftentimes having to rely upon a second party to distribute information about the study and the survey to potential respondents; consequently it was not possible to control the recruitment process or to follow-up with reminders. Also, the survey was anonymous in that there was no way to identify the respondent or even the source from which they received the survey. Even if respondents received a hard copy of the survey, they could have elected to complete the survey online.

Instrumentation

Survey Protocol Construction

Because no study was found in the literature similar to this investigation, nor was any existing data collection instruments that would address the

questions of interest in this study, it was necessary to construct a new survey protocol. The protocol was designed to capture the degree to which participant researchers felt they were meaningfully involved in the research process; the nature (both positive and negative) of their experiences; the impact of their involvement in research on their personal, interpersonal, and political lives; and their views of the usefulness of participatory models.

Protocol development began with reviewing the few first person accounts of mental health participant researchers in the literature to identify the significant domains they addressed in their descriptions of their experiences and the outcomes of their participation. Themes from these first person accounts included their feelings of validation and affirmation and the sense that their unique experiences and opinions were valued. They indicated that they had acquired new knowledge and skills and had established new relationships with those with whom they worked. These themes were consistent with accounts about what participation in settings *other* than research projects meant to them.

Additionally, the defining characteristics of empowerment (a commonly identified outcome of participation in research noted in the literature) as perceived by individuals with mental illnesses were also integrated into the survey domains. Those characteristics included: having decision-making power and access to information and resources; the ability to make choices; feeling a part of a group and that one can make a difference; learning to think critically and effecting change in one's life and community; learning skills that are defined as

important; changing others' perceptions of one's competency; and increasing one's positive self-image and overcoming stigma. The chart listing the sources for the survey questions are included in Appendix E.

Finally, in order to determine if the claims of professionals regarding the outcomes experienced by participant researchers were accurate, the various domains to which many professionals referred were incorporated into the survey as well. Thus, each item in the survey protocol was thoughtfully included based upon aspects found in the existing literature. The draft survey was then submitted to the research consultants for their review and suggested revisions. After their respective reviews, their suggested revisions (such as changes in the wording, length of items or the need for clarification) were incorporated into the instrument.

Instrument Pilot Testing

The draft survey instrument was field-tested with a convenience sample of six individuals from the faculty and staff at FMHI, four of whom are seasoned researchers. Each respondent was asked to complete the survey and to respond to a series of questions (see Appendix F) regarding the survey. They were asked to comment on: 1) the survey's length and the time it took them to complete the survey; 2) the survey format; 3) the clarity of the directions, questions and statements; 4) the appropriateness of the 9.9 reading level; 5) any language that might be offensive; and 6) the appropriateness of the offer to have the survey included in a drawing for a donation to be made to an organization or

cause of their choice. Based upon their feedback and their responses to the survey, minor changes were made to the wording of some items.

Survey Formats

After pilot testing, two formats of the final instrument were developed. The first was the hard copy version designed to be mailed, given to individuals directly, or made available for "take-one" tables at conferences or meetings. The second was a Web-based version which respondents could complete by following a link contained in the cover letter/e-mail.

Hard Copy Version.

The survey was printed in an 8½ by 11" booklet format on buff-colored paper. The booklet was seven pages in length and contained 22 questions within six sections. Twenty questions were structured, with multiple-choice response options, including three that had multiple items contained within the question and two questions that were open-ended. Questions that were open-ended or that offered "other" as a response category provided adequate spacing for written comments. In some questions, respondents were asked to check all the choices that applied, and in others they were instructed to make only one response. All the questions were grouped according to the six distinct domains of interest. These domains were created from the review of the literature described earlier and are believed to be the most salient factors that might influence respondents' views of their experiences and outcomes. Table 3.1 identifies each of the six domains.

Table 3.1

Survey Domains of Interest

Section	Domains
I	Respondents' formal education, experience and roles in research
II	The research environment
III	Respondents' experience of the research process
IV	Respondents' personal, interpersonal and political outcomes experienced
V	Respondents' endorsement of participatory research models
VI	Personal demographics

The first domain was designed to ascertain the degree to which the respondents met the criteria for inclusion in the study sample and the respondents' level of experience with research; the degree to which they were formally educated; the types of roles they had had in the research process; and the number of years and number of projects in which they had participated. In addition, they were given the opportunity, in an open-ended question, to describe the life experiences that prepared them to be involved in research.

The second section of the protocol related to the research environment, i.e., the type of organization, funding, and "culture" within which the individual had experience in conducting research. This section, while not developed specifically from the literature, was included in order to determine if the organizational auspice, the funding source, or other factors, such as mandates to

include participant researchers, were associated with respondents' views of their participation in the research process or the outcomes they achieved.

In Section III, the research experience, respondents were asked to indicate how often they had experienced certain aspects of participation in research by using a five-point Likert-type scale, with the following anchor points: "always," "most of the time," "some of the time," "rarely," and "never." They were asked about their perceptions of how they were treated as research colleagues, the degree to which they felt like authentic participants, and the degree to which they felt they benefited from the experience vis-a-vis others involved in the process.

Section IV, used a four-point scale that called for respondents to indicate whether they "strongly agree," "agree," "disagree," or "strongly disagree" with statements regarding the personal, interpersonal, and political outcomes they may have experienced as a result of their involvement in research. (A four-point scale was used rather than a five-point scale containing a "neither agree nor disagree" midpoint so that respondents would have to commit to an opinion.) The outcome domain was divided into three subcategories in order to better differentiate among personal, interpersonal, and political outcomes. In Section V, again using a four-point scale ranging from "strongly agree" to "strongly disagree," respondents were asked about their views of participatory research as a practice, i.e., whether or not they endorsed participatory research methods of research. The final section of the survey asked questions about the

demographic characteristics of respondents, such as their age, gender, race, ethnicity, and level of income.

For each question in sections I, II, and V, respondents could select the "I choose not to respond to this question" option. That option was provided to allow respondents to positively assert their prerogative to skip any question they may have felt uncomfortable answering rather than just leaving it blank. This was particularly important on the Web-based version where each question required a response before proceeding to the next question. This option allowed online respondents to opt out of a question without exiting the survey prior to completing it. Also, at the end of the survey, respondents were given an opportunity to make open-ended comments about their experiences in research that may not have already been covered. Respondents who completed the survey in hard copy could also make written comments in the margins of the survey. The full protocol is available in Appendix G.

Web-based Version.

Although there appear to be mixed reviews about the utility of Web-based surveys as compared to mail surveys (Friedman, Clusen, and Hartzell, 2004), a Web-based option was provided to respondents because 1) mailing addresses for potential respondents were not always known, especially if they were among those who received the cover letter and survey from someone else; 2) it was believed that a number of respondents may work in, or have access to, settings where they have access to the Internet; 3) it was possible to reach a larger

number of individuals/organizations more efficiently, i.e., the turn-around time for responses was not dependent upon the mail systems; and 4) it was easier for those researchers who were contacted via e-mail and asked to assist with reaching others with the survey to forward e-mail attachments (cover letter and survey) to potential respondents. It was also possible that respondents might have preferred to complete an online survey rather than a hard copy.

The electronic survey vendor, Survey Monkey®, was selected and engaged because it had the appropriate security procedures (See Appendix H), it was easy to use, and it was relatively inexpensive. The vendor stored the data on a secure SQL server that was backed up daily and allowed for the data to be exported to a spreadsheet or statistical program.

Advice regarding the online survey layout was obtained from individuals at FMHI who had previous experience designing Web-based surveys. In particular, they suggested changes in lay-out that would keep the navigation buttons within view (without the respondent having to scroll down) to provide respondents the sense that they were moving forward in completing the survey. They also suggested changes to wording of the questions and response options. These suggestions were incorporated in the survey prior to the online version being field-tested.

The electronic version of the survey was field-tested by a small convenience sample of staff and faculty at FMHI who were asked to complete the online survey from various computers (e.g., their home as well as their office

machines) and to report any difficulties they may have had in accessing, completing, or exiting the survey. Based upon their feedback, the online survey was amended to give respondents the option of requesting a hard copy of the survey if they experienced difficulty completing the electronic version.

The Web-based survey contained the same questions as the hard copy version; only the survey format varied. There was one additional question on the online version, however, at the very beginning of the survey. Respondents were asked if they were completing the survey online in lieu of a hard copy version that they may have received. This question was designed to determine respondent preference and to assess the relative utility of the Web-based version.

Questions on the Web-based version were designed so that, with very few exceptions, respondents had to complete an item before proceeding to the next item. However, as in the printed version of the survey, respondents could select the "I choose not to answer this question" as a response in sections I, II, and V. Respondents could also choose not to complete the online survey by closing their browser, at which point their incomplete survey was included in the electronic database.

Open-ended questions for respondents were also included in the Web-based version (e.g., "What life experiences have helped prepare you for your involvement in mental health research?") and at the end of the survey ("Are there any comments you would like to make regarding your participation in research that might not have been covered in this questionnaire?"). However, unlike the

hard copy version, respondents had no way of writing in comments on other items.

Procedures

Protection of Human Subjects

Prior to implementing the study, an application that included the language for the survey cover letters and a copy of the survey was made to the Interdisciplinary Committee on Ethics in Human Research (ICEHR) at Memorial University (See Appendix I). As a courtesy, copies of the materials were provided to the Ethics Review Board at the University of South Florida (USF), home institution of the investigator. (See Appendix J) The USF Ethics Board agreed to defer to the Memorial Interdisciplinary Committee on Ethics in Human Research regarding oversight for this research. (See Appendix K)

The ICEHR requested that changes be made to the cover letter for the survey. (See Appendix L) Each concern was addressed and a letter indicating the changes that had been made was sent to the Committee for their approval (See Appendix M). Final approval to proceed was received on October 31, 2003. (See Appendix N). Yearly status reports have been made to the Committee since the initial approval was received.

Given the potential vulnerability of the individuals who may have participated in the survey and the sensitive nature of some of the items included on the survey, every effort was made to protect the identities of individuals being recruited for the survey and the respondents. Hard copy surveys did not request

any identifying information. The return self-addressed envelopes had the investigator's address in the upper left corner as well so that respondents did not include their own return address and every envelope was stamped "confidential". All paper surveys and any accompanying materials (e.g., envelopes, letters, notes) received were maintained and stored in a locked file cabinet in a locked closet within a locked office. Also, survey results are being reported only in the aggregate, consequently, no responses can be attributed to any particular individual.

The Web-based version of the survey was anonymous, as there were no questions that asked for identifying information and there was no way to track responses to any individual. Web-based survey responses and any other e-mail correspondence received from respondents were kept on a limited access, password protected computer within a locked office.

Finally, individuals who were asked to forward the survey (either by mail or e-mail) to other potential respondents, were asked *not* to send the names or contact information of those individuals to the investigator, but rather to give the potential respondents the investigator's contact information should *they* choose to participate or have questions. Also the individuals who received surveys from other colleagues through the snowball sampling approach were advised that they were under no obligation to tell the individual from whom they received the survey whether or not they participated.

Survey Administration

The initial mailing list for the surveys included 30 individuals who were identified from lists of attendees at the NRI national research conference and through the literature and for whom mailing addresses were available. That list included names of well-known researchers as well as those who had identified themselves as consumers/advocates and were noted as such on the list of conference attendees. Those 30 individuals received a mailed version of the survey with a cover letter in a first class postage-paid envelope which included the survey and a return self-addressed, postage-paid envelope marked confidential. In the cover letter, they were also given the link to the Web-based version of the survey in the event they preferred to complete the survey online. Those individuals on the mail list who were already known to be researchers were mailed three additional cover letters with copies of the survey and postage-paid self-addressed envelopes marked "confidential". They were requested to distribute the additional letters of invitation and the survey to other individuals with whom they might have contact and who might meet the criteria for inclusion in the study. Follow-up post-cards were mailed after two weeks as a reminder to complete the survey if they had not already done so.

Of the 30 envelopes that were mailed, 12 (40%) were returned for incorrect addresses or marked "unknown" at that address. Because of the length of time it took to receive the returned envelopes, the follow-up post-cards were already mailed but were also subsequently returned. Given the problems of

locating correct mailing addresses and the extended time and expense that were required for mailings, the use of e-mail became the primary mode of survey distribution. However, hard copy surveys were still provided to anyone who requested them and were used for distribution at meetings and conferences.

Fifty-seven e-mails were sent either to individuals who were known as participant researchers or other research professionals who were known to have included participant researchers in their work. Those individuals who were known as participant researchers were sent information about the study with a copy of the cover letter and the survey as an attachment to the e-mail. They were invited to participate in the study by either printing a copy of the survey at the end of the cover letter or by using the link to the Web-based version of the survey to complete it online. They were also asked to forward the attachments (the cover letter and survey) to other potential respondents they believed might meet the criteria for inclusion in the study. The professional researchers who also were e-mailed were asked to share the information about the study with participant researchers with whom they may have worked by forwarding them the cover letter and survey.

Data collection began in September 2005 and concluded in August 2006, allowing almost a full year for respondents to receive and return mailed/e-mailed surveys or to respond via the Web-based version.

Data Analysis

A total of 90 surveys were received. Because of the methods for respondent recruitment (snowball and opportunistic, convenience sampling) and the fact that the size of the population of interest (participant researchers with mental illnesses) was unknown, it was not possible to calculate a response rate for this survey. Sixty-four surveys (71%) were received via the online format and 26 surveys (29%) were received in hard copy (only ten of which were completed on the original hard copy provided; others were either photocopies or printed e-mailed versions of the survey). Of the 90 surveys received, 72 (80%) surveys had sufficient data to be included in the analyses.

As hard copy surveys were received, they were numbered consecutively and entered into the online database. The number corresponding to the survey was then added to the first open-ended response option in the online database in order to be able to track that entry in the online database to the original hard copy source of the survey. This was especially important to capture and track any comments that were marked in margins of the hard copy of the survey. Because three hard copy surveys were received with missing items, they were entered directly into the data analysis program (SPSS v14) because the Web-based format did not allow for missing items. On hard copy versions of the survey where respondents were asked to check only one response, but checked more than one, the response with the highest value or the first response was entered as their response for that question. If their markings on the hard copy

were not clear, the answer recorded was that which appeared most consistent with their other answers.

Data Reduction

Raw data from the online database was initially summarized through the online survey vendor, providing the total number of respondents (N) per question, the number of participants who failed to answer each question, the percent of respondents for each response category for each question, and the individual text responses to open-ended questions. The online data were then exported to a Microsoft Excel database from which the data were entered into the data analysis program, SPSS v14. Text responses were exported into a Word document for content analysis as described below.

Once the data were entered into the data analysis program, variable names were created and items were recoded to ensure that the most positive response on the scales received the highest score and the least positive response received the lowest score. Items that contained response options that were considered to be hierarchical (such as participant roles in research and participant credentials) were recoded to ensure that the response with the highest value received the highest score and the response with the least value received the lowest score. For example, a doctoral degree was given a higher score than a master's or bachelor's degree, given that a doctoral degree is considered a terminal degree requiring additional years of preparation beyond the master's or bachelor's level. Descriptive statistics, including frequencies,

means, variances, standard deviations, and skewness measures were then conducted to determine the normality of the data.

Scale and Variable Construction

Five scales were constructed to measure the domains of interest: 1) the degree to which respondents' experiences in research were participatory; 2) the personal outcomes; 3) interpersonal outcomes; 4) political outcomes experienced by respondents as a result of their participation in research; and 5) the level of endorsement of participatory models of research by respondents. The extent of respondents' research experience was constructed as a composite variable. Table 3.2 details the specific items that are associated with each scale/variable. Determinations about which items to include in each scale were based upon the degree to which each item related to the construct of interest.

Table 3.2

Survey Scale Items

Scale/Composite Variable Title	Number of Items	Item Number Included in Scales/Variable
Extent of Experience	4[a]	3, 4, 5, 8
Degree of "Participatoriness"	20	14a - 14t
Outcomes Subscales		
Personal	12	15a - 15d; 15g, 15h, 15j, 15m - 15q
Interpersonal	4	15f; 15i, 15k,15q
Political	4	15d; 15e; 15l; 15r
Endorsement of Participatory Research	10	16a - 16j

[a]*There were four questions that made up this composite variable, however one question had 10 response options that were treated as separate items.*

Extent of Experience.

The experience variable reflected the extent of the respondent's experience, including whether or not they were employed as a researcher and the length of time they have been involved in research, as well as the number of research projects in which they have been involved and the roles they had in the research process. Employment as a researcher was scored higher than volunteering on research projects. Similarly, the more years of experience and the greater number of projects with which respondents were involved, the higher their score on the experience scale. The final item in this composite variable--the roles that respondents have had in their research experiences--was also scored differentially, based upon assumptions regarding the roles which required more preparation, skill, involvement, and control over the research process. Directing or co-directing projects received a higher score than designing studies; however, designing studies was scored higher than writing up the research results. Similarly, presenting findings at a conference or workshop received a higher score than collecting, entering, or analyzing data. Serving as an advisor to a project was scored the lowest among the roles.

"Participatoriness" of the Research Experience.

The term "participatoriness" was created for use in this study as a concise way of referring to the concept of participation as a continuous variable. All 20 items in this domain comprise the scale that measures respondents' views about the degree to which they felt they were authentic partners in the research

process. Items on this scale were derived primarily from the literature, as noted earlier, where first person accounts of their research experience identified issues that were relevant to them, e.g., that they felt safe in expressing their views, that their views and recommendations were valued and often acted upon, and that they felt they had an equal role in decision making. Items were also included that participant researchers had indicated were difficult for them, e.g., not being asked to participate in all phases of the research, not feeling they could trust the other professionals with whom they worked, or believing that professionals were unwilling to share their power.

Respondent Outcomes.

Personal, interpersonal, and political outcomes were included as subscales in the outcomes domain in order to capture change in these three different dimensions of a person's life. For purposes of this study, personal change reflects changes within a person's own life or lifestyle. It encompasses how a person views himself or herself and their abilities, their sense of control over their life, and having and making choices. Interpersonal change reflects changes in one's interaction with others, such as in families, work, and other social relationships. It is how they relate to others and how others relate to them. Political change, as defined here, is the change that people experience in their relationships to their broader community and the institutions that make policies affecting their lives, such as local and state agencies and governing bodies. Because individuals may experience changes differentially among these three

constructs, they are being examined separately. However, respondents were asked to consider their overall experiences in research and the effects that those experiences have had on their lives, without their identifying the items as relating to their personal, interpersonal, or political outcomes.

Personal Outcomes

The 12 items that were included in the personal outcomes measure were identified in the literature by individuals who were reporting their experiences of participating in research projects with other professionals. These items were also found in the literature as elements of empowerment.

Respondents were asked to indicate their degree of agreement/disagreement with 12 statements that included: they were able to make positive changes in their lives; they have more self-confidence; they understand their own mental illness better; they have received economic benefit from their involvement; and they are better self-advocates.

Interpersonal Outcomes

Four items are included in the interpersonal outcomes measure. As indicated in the above discussion relating to personal outcomes, the items relating to interpersonal outcomes also were identified from personal accounts by participant researchers found in the literature as well as the professionals' accounts of what participant researchers have experienced.

Survey respondents were asked to indicate their degree of agreement/disagreement with the four statements that comprised the

interpersonal outcome scale including: they have made new friends among the others with whom they have participated in research their friends with mental illnesses no longer associate with them; people seem to respect their opinions more than previously; and they have become better known as researchers.

Political Outcomes

Four items comprised the scale measuring the effect that participating in research has had on the individual's political life, i.e., the involvement they have in their communities beyond their interpersonal relationships. The items in this scale were also identified in the literature, both by participant researchers and the professionals who had worked with them.

Survey respondents were asked to indicate their degree of agreement/disagreement with the following statements: "I am a better advocate for myself," "I am more willing to advocate for other people with mental illnesses," "I have been able to affect decisions about mental health policies or practices," and "I have been able to positively affect other people's attitudes about working with people who have a mental illness."

Endorsement of Participatory Methods.

The ten items that comprise the scale measuring endorsement of participatory methods of research were derived from the literature which supports the use of participatory research methods, as well as earlier work by the investigator in which a series of focus groups were conducted with professionals

from a research institute regarding their views of participatory models of research (Robinson, 2003)

Respondents were asked to indicate the degree to which they agreed/disagreed with statements regarding the utility, feasibility, and efficacy of participatory research methods. Examples of statements included: "Involving people with mental illnesses in mental health research improves the research process and outcomes," "It is not always practical or desirable to include people with mental illnesses in mental health research," and "People with mental illnesses should do their own mental health research, not just participate in mental health research done by other professional researchers."

Instrument Validity and Reliability

Assessment of Validity.

Because there were no existing survey instruments found in the literature that systematically assessed experiences and outcomes of participant researchers, especially for those individuals with mental illnesses, an instrument had to be developed that would address the explicit questions of interest in this study. (The details of the sources and process for instrument development were described earlier.) Thus, the validity and reliability of the constructed instrument were unknown. However, the items within each domain of interest were derived from the literature wherein the personal views of individuals who were likely to be similar to the individuals recruited as respondents for this survey were expressed. Additionally, the content items in each domain were reviewed by the

consumer researcher consultants to this project. Therefore, it is reasonable to assume that the items contained on the survey at least have construct validity.

Assessment of Reliability.

The internal consistency of the scales described above was measured by computing Cronbach's Alpha for each scale. Cronbach's Alpha, a procedure commonly used with cross-sectional data, renders a coefficient that is an indication of the internal consistency of the scale items (Selltiz, Jahoda, Deutsch, and Cook, 1967). Cronbach's Alpha represents the average of all possible split-half reliabilities. The closer the coefficient is to one, the more reliable the measure is (Abu-Bader, 2006, p. 7). As can be seen in Table 3.3, the scale representing the respondents' perceptions of the degree of "participatoriness" in their research experiences has the highest degree of internal consistency (.90). Scales measuring personal and political outcomes have similar Alpha coefficients (.73 and .77, respectively). The scale items related to the respondents' endorsement of participatory research models has the second lowest Alpha (.62), and the subscale relating to respondents' perceptions of their interpersonal outcomes has the lowest Alpha coefficient (.52).

Initially, there were five items that comprised the interpersonal outcome scale, but after examining the item to total statistics for this scale to determine if removing an item would improve the Alpha coefficient, the following item was eliminated from the scale: "I have been asked to participate in research projects so often that it has become a problem for me."

Another factor that may have contributed to the low Alpha coefficient for the interpersonal scale is the fact that it contains only four items. Generally, the more items there are in a scale designed to measure a particular concept, the more reliable the measurement will be (Abu-Bader, 2006).

While reliability coefficients of .60 have been used by some social services researchers, a coefficient of .70 is considered more acceptable for a scale. (Abu-Bader, 2006). Hence, the Alpha coefficients for the endorsement and interpersonal outcome scales are either just above or below the acceptable range. However, for purposes of this exploratory study it is useful to examine all the results, with the caveat that the interpersonal scale and the scale measuring respondents' endorsement of participatory methods of research are less reliable.

Table 3.3.

Scale/Composite Variable Descriptive Statistics

Scale/Variable	N	# of items	Possible range	Actual range	Mean	SD	Alpha
Experience – Respondents' level of experience in research	72	13[b]	0-51.5	0-50	23.2	12.7	NA
Participate – The degree of participatoriness of respondents' research experience	72	20	20-100	46-100	79.2	12.1	.90
Personal Outcomes – Changes in respondents' quality of life	70	12	12-48	28-47	37.2	4.5	.73
Interpersonal Outcomes – Changes in respondents' social relationships	70	4	4-16	9-16	12.6	1.7	.52

Table 3.3. Continued

Scale/Composite Variable Descriptive Statistics

Scale/Variable	N	# of items	Possible range	Actual range	Mean	SD	Alpha
Political Outcome – Changes in respondents' political involvement	70	4	4-16	7-16	13.0	2.1	.77
Endorsement – Respondents' perceptions of participatory research methods	69	10	4-40	24-40	31.1	3.4	.62

[b]There were four questions that made up this composite variable, however one question had 10 response options that were treated separately

Quantitative Analyses

To determine the factors that may be associated with a person's outcomes and their views of participatory methods of research, Pearson product-moment correlation coefficients were computed among the scales/composite variable scores for the: 1) respondents' level of experience; 2) participatoriness of the research experience; 3) personal outcomes; 4) interpersonal outcomes; 5) political outcomes; and 6) endorsement of participatory methods. One-way ANOVAs were run to determine the relationship between the research environment and participatoriness and between the research environment and the three outcome measures.

Qualitative Analyses

Four questions on the survey provided respondents opportunities to provide additional comments, two provided an "other" category in addition to other response options, and two were completely open-ended. Specifically,

respondents could indicate any other specialized training they may have had that would have helped prepare them to do research, in addition to or instead of formal credentials. They were also asked about the life experiences they may have had that would have helped prepare them for involvement in mental health research. When asked about their roles in participating in research, they could identify any additional functions they may have had as part of the "other" response category. At the end of the survey, respondents were given an opportunity to make any additional comments they chose that might not have been covered in the questionnaire.

Of the 26 respondents who chose to return a hard copy of the survey, three made additional comments in the margins of the survey booklet and 14 others contacted the investigator by e-mail with additional comments, questions, or suggestions. Every e-mail contact was acknowledged and in some instances, resulted in more than one contact with the respondent.

Qualitative comments, including those that were written in the margins of the hard copy surveys and those that were e-mailed to the investigator were exported into a Word document. Because of the relatively small number of text responses received and the little advantage to be gained by the use of a computerized analysis program, (Lofland and Lofland, 1995), it was determined that the use of qualitative data analysis software was not warranted. Rather, responses to open-ended questions were printed, cut into strips and sorted into groups, with similar items placed together. This procedure was repeated twice to

ensure that the first impression of the response and its subsequent placement within a group was accurate. The distinct groups were then labeled according to the overall theme represented by the content. For example, the "other" formal credentials noted by respondents were initially sorted into eight categories: additional formal education; formal education, but less than a degree; consumer training; unrelated training; employment (including consulting); unrelated employment; experience with a mental illness; and unrelated life experiences. Given the small number of cases in each of the eight categories, the number of categories was finally reduced to three major areas: additional education; additional training; and work experience (including paid or unpaid).

Responses to the question "What life experiences have helped prepare you for your involvement in mental health research?" were sorted into four major categories that included: having a personal experience with a mental illness; having a personal experience with a mental illness and/or family experience with a mental illness; having a mental illness and/or formal education or training; and having a mental illness and/or work experience (including paid or unpaid).

With respect to the "other" roles that respondents indicated that they had had in their research experience, either in addition to or instead of those provided in the survey, they were coded in three major categories: serving as consultants/advisors; providing technical support; and managing/supervising some aspect of the research.

The last question of the survey was open-ended and asked if there were any other comments that the respondent would like to make. Content analysis was conducted on the responses as well as the e-mails from participants.

Text responses were shared with two of the consultants who agreed to review them and provide comment. Neither of the consultants was able to conduct their own coding of the responses, but they did offer insights to what the responses may have meant. Their comments, however, did not change any of the previous decisions regarding how items were coded or the identified themes.

Finally, a draft of the study findings (both quantitative as well as qualitative) was also forwarded to two of the consultants by e-mail to solicit their feedback regarding the overall results from the survey. They were asked to comment on the data as well as the investigator's characterization of the findings.

CHAPTER FOUR

RESULTS

In the literature, a central theme regarding participatory research is that individuals who participate in the research process are empowered. However, there are few personal accounts by participant researchers regarding the benefits they may have derived from their experiences. The purpose of this study was to obtain participant researchers' perspectives about their experiences. Specifically, the study focused on individuals who had mental illnesses and had been involved in research in a role other than as a respondent or subject to determine if they perceived that they were empowered through that experience and, as a result, made changes in their personal, interpersonal, and political lives.

The specific questions this study addressed were:

1. To what degree have participant researchers felt they were meaningfully involved in the research process?
2. What factors contributed to their characterization of their experiences?
3. What is the relationship of participation in research to their personal, interpersonal, and political lives?
4. What are their views about the feasibility and utility of participatory research models?

The results of this study are provided in this chapter in the order of these specific research questions. However, prior to addressing the findings related to the

above questions, the following information describes the study sample, the participants' demographic characteristics, and the extent of their experience as researchers, as well as the types of roles they have had in research projects. Additional information is provided about the research environments in which they have worked as researchers

The study sample

Recruitment for this study resulted in 90 individuals responding to the survey. Twenty-six respondents completed the hard copy version of the survey (29%), and 64 (71%) completed the Web-based version, which indicates that the Web-based version of the survey was a successful option for the majority of individuals. In fact, 50 of the 64 respondents (almost 78%) who completed the Web-based version indicated they were completing the survey online instead of the hard copy form that they had received. However, of the 64 individuals, 20 individuals apparently exited the survey prior to completing it by closing their Web browser, which is reflected in the attrition figures noted in Table 4.1 below. As seen from the table, the largest drop in participation was early in the survey (between questions 1 and 4).

Twenty-three of the hard copies of the survey that were received were entered into the online data base for a total of 87 surveys. The remaining three surveys were entered directly into the data analysis software because they had missing items, which the online version did not accommodate. (With few exceptions, each answer required a response before the respondent could

proceed to the next question). Of the original 90 responses, 72 (80%) of the cases had sufficient information to be included in the analyses.

Table 4.1

Online Survey Response Figures

Question #	N	%
1	87*	100
2	81	93
3 – 4	77	88
5	75	86
6 – 11	73	84
12 -13	72	83
14 -15	71	82
16 -20	69	79
21 -31	67	77

*Includes 23 hard copy versions entered into the database.

Respondent Characteristics

As was noted in Chapter Three, there is no way to compute a response rate for the overall study given the multiple methods used for recruiting respondents and the lack of information about the size and nature of the study population. Also, there is no way to determine how representative this study sample may be of the larger population of consumer/survivor participant researchers. However, of the individuals who responded to these items on the survey, the majority (64%) was female and was 41 years of age or older (78%).

There were very few minorities among the respondents (approximately 10%), and only one person identified himself/herself as Hispanic (1.5%). Slightly more than a third of respondents (34%) reported incomes that fell within the $20,000-$39,999 range, however almost another third (30%) reported annual incomes below $20,000.

The survey also assessed the extent of respondents' formal credentials and/or training that may have helped prepare them to do research as well as the extent of their research experience. When asked about their formal education, more than half of the respondents reported having completed post secondary education. Twenty-four percent of respondents reported having a bachelor's degree and 26% reported having a master's degree and seven people (13%) reported having a doctoral degree. Only one person (2%) indicated that he/she had no formal credentials. Table 4.2 provides the details regarding the demographic characteristics of the survey respondents.

Table 4.2

Respondent Characteristics

Characteristics	N	%
Gender:		
Male	25	36.2
Female	44	63.8
Age:		
21-30	3	4.3
31-40	12	17.4
41-55	28	40.6
55+	26	37.8

Table 4.2 Continued

Respondent Characteristics

Characteristics	N	%
Race:		
White	58	89.2
Black	1	1.5
Native American	1	1.5
Other	5	7.7
Hispanic:		
Yes	1	1.5
No	64	98.5
Income:		
$5,000-$19,999	18	29.5
$20,000-$39,999	21	34.4
$40,000-$59,999	12	19.7
$60,000-$79,999	3	4.9
$80,000+	7	11.5
Formal credentials:		
Bachelor's Degree	13	24.5
Master's Degree	14	26.4
Doctoral Degree	7	13.2
Other Specialized Training	18	34.0
No Formal Credentials	1	1.9

In addition to the closed-ended response options in the question about their formal credentials, respondents were given the opportunity to indicate any other types of specialized training that they might have had to help prepare them to do research. Twenty-one respondents chose to provide additional information. Their responses could be categorized into three major areas: additional formal education; additional training; and some type of work-related experiences (paid or unpaid, unspecified). Nine of the 21 respondents cited having additional formal education which included "two years post-graduate studies," " two

courses short of a master's degree...," and "[having a] JD," while six respondents cited having additional training that included "consumer consultant training" and "qualitative software [training]." A third of the respondents indicated that they had work-related experience that helped prepare them to do research as noted by their following responses: "11 years in mental health service provision," "Teacher, primary and special [education]," and "Advocacy."

Respondents' Research Experience

Respondents were asked about the number of years of experience they had participating in research, the number of research projects in which they have been involved, and the types of roles they have had in those projects. Almost half of the respondents were not employed (45.9%) but did get paid for the work they did as researchers. Another 16% reported being unemployed but volunteering to work on research projects. Almost 37% reported being involved in research for ten or more years. However, 43.5% indicated that they had been involved with research for four or fewer years, with 13% of those individuals indicating that they had one year or less experience. Thus, the sample in this study consists of both experienced and relatively new researchers.

The large majority of respondents (87%) reported that they had been involved in fewer than four research projects in the past three years, which is not surprising, given that projects often last longer than one year and can take considerable time and effort to complete.

Respondents were also asked to indicate the primary roles they have had in research projects. As can be seen in Table 4.3, the results are fairly evenly distributed across the different roles, indicating that respondents have carried a variety of responsibilities; however, the most often cited roles were: "analyzing data" (41%) "collecting data" (44%); "presenting results at conferences/workshops" (49%); "writing up research results" (40%); and "serving as an advisor" (40%).

Table 4.3

Respondents' Level of Experience

Experience	N	%
Employed primarily as a researcher:		
Yes	14	37.8
Unemployed, but paid for work on research projects	17	45.9
Unemployed, but volunteer on research projects	6	16.2
Length of time involved in research:		
10 yrs+	28	36.8
5-9 yrs	15	19.7
2-4 yrs	23	30.3
One year or less	10	13.2
Number of projects in the last three years:		
10+	2	2.7
5-9	8	10.7
2-4	41	54.7
Only one	24	32.0
Primary roles in research: [a]		
Director/Co-director	23	25.6
Designing research studies	33	36.7
Analyzing data	37	41.1
Writing up research results	36	40.0
Presenting results at conferences/workshops	44	48.9
Collecting data	40	44.4
Entering data	22	24.4
Serving as an advisor	36	40.0

[a]Percentages total more than100% because respondents could select more then one response.

Respondents were also given the opportunity to indicate any other roles (other than those provided in the survey) that they may have had. Sixteen respondents chose to provide additional information. Three categories were identified from their responses, including: consulting or advising; providing technical support; and managing some aspects of projects. Seven respondents indicated that they had been involved as a consultant/advisor, as illustrated by the following comments: "Consumer consultant;" "member, government expert panel guiding research decisions;" and "...chaired empowerment subcommittee for that section of the research design." Three respondents indicated that they had provided technical support to the project, including "[providing] technical support;" and "creating spreadsheets, tables, graphs, Powerpoint presentations, budgets;" and two individuals indicated that they had managed some aspect of the project, as noted by their comments "Managing data collectors" and "[serving] as project manager." Other roles that were mentioned included training of interviewers and monitoring programs.

Other Life Experiences

Respondents were asked, in an open-ended question, about the life experiences they may have had that helped prepare them for their involvement in mental health research. Sixty-seven respondents provided text answers to the question. After conducting content analysis on the text responses, four major themes emerged: having a personal experience with a mental illness; having a

personal experience with a mental illness and/or a family member with a mental illness; having a mental illness and/or a work-related experience (paid or unpaid unspecified); and having a mental illness and/or education or training. With few exceptions, people indicated that their personal experience with a mental illness was helpful in preparing them to participate in mental health research. In fact, a third of the respondents (22) cited their own personal experience with a mental illness as having helped them to do mental health research, as evidenced by some of the comments they shared: "I was diagnosed and treated as 'mentally ill';" "[I had] Approximately 16 psychiatric admissions;" and "my illness;" while 11 others, (almost 16%) cited having a mental illness and/or a family member with a mental illness as contributing to their ability to participate in research. Their comments included: "My father's suicide, my own mental illness;" and "Father - suicide, brother – suicide, myself [sic] depression, Father-in-law – bipolar;" and "My husband and I both suffer from mental illness..."

Other respondents (20) referred to having been a recipient of services and their work-related experiences as having been helpful in preparing them for their involvement in research, as noted by the following examples of their remarks: "Experience as a recipient, provider, manager of many services...;" "personal mental illness, lots of volunteer work;" and "volunteer, consumer, provider of mental health services." Almost a quarter of the respondents reported that their own mental illness and/or their education or training helped prepare them to do research. Some of the comments they made included: "training by people

conducting research...My formal education, my life experiences with mental health issues;" "graduate study in psychology, mental health promotion and advocacy work, personal disabling experience of substance addiction, depression, etc;" and "training as a researcher at various university research settings..."

From these comments, it is clear that among these respondents, their personal experience with a mental illness was a major factor that helped them to participate in mental health research.

The Research Environment

One feature of the research process that may relate to the research experience is the environment in which the research is conducted. For example, was there a requirement to include participant researchers in the process? Were there others who also had mental illnesses involved? For purposes of this study, the research environment included not only the type of agency and funding that provided for the research but also whether there was awareness among other professionals that the person(s) participating in the research had experience with a mental illness as well as whether or not there were others participating who also had a mental illness. While there were no a priori assumptions made about the influence of the research environment, there are instances in which participatory research methodologies may be required by the funding source or by the organization within which the research is conducted. Also, having others known to have a mental illness participating in the research may make the

environment more conducive for participant researchers to express their opinions (Whitley, 2005). Therefore, respondents were asked to indicate whether the other members of the research teams knew that they had a mental illness and whether or not there were others involved who also had a mental illness.

Table 4.4 shows the types of agencies/organizations within which the research was carried out as well as the funding sources for most of the research. It also includes how often it was known that the participant researchers had a mental illness and whether there were others involved who also had a mental illness.

As can be seen from the table, in almost all instances, it was known that the participant researcher had experience with a mental illness and that more often than not, there were others participating who also had mental illnesses. In the large majority of the cases, there were requirements to involve people with mental illness in the research. Not surprisingly, the requirement to involve individuals with mental illnesses in the research was found to be significantly, positively correlated with more than one person being involved ($r=.927$, $p <.01$).

The government was most often cited as the source of funding for research, and the research was generally carried out in universities or service-providing agencies, although government agencies were also noted as frequent research sites.

Table 4.4

Characteristics of the Research Environment

Characteristics	N	%
Respondents were known to have a mental illness:		
All the time	56	76.7
Some of the time	15	20.5
No, didn't believe others knew	2	2.7
Others with mental illnesses were involved:		
All of the time	27	37.0
Some of the time	38	52.1
Rarely	7	9.6
Never	1	1.4
Type of agency in which research was conducted:		
Government	18	24.7
University	22	30.1
Private	10	13.7
Service Provider	23	31.5
Sources of research funding:[a]		
Government	55	67.9
Foundation	15	18.5
Private	11	13.6
No external funding	2	2.5
Required to have people with mental illnesses involved:	30	43.5
Yes, in all cases	26	37.7
Yes, in some cases	1	1.4
No, but customary	12	17.4
No		

[a]Percentages could total more than100% because respondents could select more then one response.

The Research Questions

To what degree have participant researchers felt they were meaningfully involved in the research process?

Participatoriness

Survey respondents were asked to characterize their experiences as participant researchers by responding to a series of statements that related to important aspects of participation. These were derived from participant researcher accounts in the literature in which participant researchers described their positive experiences. Respondents were instructed to consider their *overall* research experiences when indicating how often the 20 statements were reflective of their own experiences. These statements comprised the Participatoriness scale as described in Chapter Three.

Seventy-two respondents completed the 20 items on the "participatoriness" scale. They were asked to indicate on a five-point Likert-type scale (with 5 being the highest positive value and 1 being the lowest) whether the statement was "always," "most of the time," "some of the time," "rarely," or "never" reflective of their experiences. The possible range of scores for the scale was 20 -100, and the observed range was 46 -100. The mean scale score was 79.2, (SD=12.06), indicating that the results were negatively skewed and that respondents generally characterized their experiences as positive. As can be seen from Table 4.5, while respondents were generally positive about their involvement in research, there were some items in the scale that were rated higher than others.

Table 4.5

Participatory Scale Items (N=72)

Scale Item	Mean	SD	Range	Skewness
If I needed help in understanding research language and methods, other researchers willingly explained them*	4.33	.99	1-5	-1.70
Other researchers treated me with respect*	4.24	.70	3-5	-.37
It was safe to express my opinions*	4.21	.77	3-5	-.38
I had enough time and assistance to be prepared to be a full participant*	4.19	.90	2-5	-.64
I received good feedback from other researchers about my contributions*	4.17	.87	2-5	-.73
I had many opportunities to share my concerns, questions, perspectives with other researchers*	4.15	.78	3-5	-.28
Symptoms of my mental illness often prevented me from being a full participant	4.15	.82	2-5	-.45
If I needed special accommodations they were provided for me without negative consequences*	4.10	1.02	1-5	-.85
I did not feel like part of the research team because I was included in most of the research activities	4.07	.98	1-5	-1.06
My expenses were adequately covered*	4.04	1.23	1-5	-1.26
I had the same access to resources as other researchers had*	3.99	.14	1-5	-.90
My views and recommendations were valued and acted upon*	3.98	.64	3-5	.01
I did not feel like I could really trust the other professionals with whom I worked	3.90	.95	2-5	-.51
I was paid fairly for the work I did*	3.86	1.28	1-5	-.81
I felt welcome to participate in the research activities, but did not feel would be invited to socialize with other researchers	3.82	1.15	1-5	-.60
I was encouraged by others to assume more responsibility*	3.78	1.10	1-5	-.58
I was asked to participate in all phases of the research*	3.72	1.19	1-5	-.68
I had an equal role in decision making*	3.61	.16	1-5	-.53
Professional researchers were willing to share their power	3.50	1.19	1-5	-.34
It was acceptable for me to seek emotional support from the other researchers*	3.40	1.31	1-5	-.29
Overall Scale Statistics	79.20	12.06	46-100	-.48

*These items were reverse coded

Within the 20-item scale, the five items which were most highly endorsed were: "If needed help with understanding research language and methods, other researchers willingly explained them to me;" "Other researchers treated me with respect;" "It was safe to express my opinions;" "I had enough time and assistance to become adequately prepared to be a full participant;" and "I received good feedback from the other researchers regarding my contributions".

The five items which were endorsed the least included: "It was acceptable for me to seek emotional support from the other researchers when I needed it;" "The professional researchers were willing to share their power;" "I had an equal role in decision making;" "I was asked to participate in all phases of the research, including determining what research questions would be addressed;" and "I was encouraged by other researchers to assume more responsibility."

In comparing the items that were rated highest to those that received the lowest levels of endorsement, it appeared that respondents believed that they were "accepted" as part of the research environment and were accommodated in terms of their preparation for participation in the research process, but they were less likely to feel they were equal partners. They did not feel that professional researchers were willing to share their power or that they (the respondents) had an equal role in decision making. They also did not feel that they shared in all phases in the research process. This finding is somewhat surprising given the levels of education and years of experience in research that were reported by many of these respondents. However, this finding is consistent with comments

made by some respondents at the end of the survey, where they reported that they felt they were treated respectfully but were still not fully integrated into the entire research process.

What is the relationship of participation in research to their personal, interpersonal, and political lives?

Respondents were asked to respond to a series of statements that related to the personal, interpersonal, and political outcomes they may have achieved as a result of their participation in research. These statements were reflective of the outcomes of participant researchers that have been described in the literature (most often by professionals) as resulting from the research experience. Three outcomes subscales (personal, interpersonal, and political) were created to disaggregate the overall outcome which has been described as "empowerment" (Rogers et al.1999).

Personal Outcomes

The first subscale was designed to assess the degree to which respondents have experienced positive changes in their personal lives, e.g., "I have more confidence in myself;" "I have been able to make positive changes in the way I live." There were 12 statements in this subscale on which respondents were asked to indicate on a four-point scale whether they strongly agreed, agreed, disagreed, or strongly disagreed (with 4 being the highest positive value and 1 being the lowest). The possible range of scores was 12-48, and the observed range was 28-47. The scale mean was 37.2 (SD=4.5) and the

distribution was negatively skewed, which indicates that respondents generally agreed that they had experienced positive changes in their personal lives as a result of participating in research. Table 4.6 displays the 12 items that make up the personal outcomes scale.

Table 4.6

Personal Subscale Items (N=72)

Scale Item	Mean	SD	Range	Skewness
I lost important benefits	3.54	.65	1-4	-1.43
Everyone, but me, benefited from my contributions to the research	3.47	.53	2-4	-.18
My health has been adversely affected	3.34	.76	1-4	-1.08
I learned new job skills*	3.31	.72	1-4	-.77
I have been asked to participate in research projects so often it has become a problem for me	3.30	.70	1-4	-1.01
I have more confidence in myself*	3.25	.69	2-4	-.37
I have been able to make positive changes in the way I live*	3.22	.72	2-4	-.36
I am a better advocate for myself*	3.15	.73	2-4	-.24
I have been offered other types of work*	2.80	.83	1-4	-.67
I have become better known as a researcher*	2.72	.76	1-4	-.11
I understand my own mental illness better*	2.71	.90	1-4	-.37
I have received promotions/pay increases at work*	2.32	.93	1-4	.18
Overall Scale Statistics	37.20	4.50	28-47	.09

*These items were reverse coded

The items which had the greatest level of endorsement were that respondents did not feel that they had lost benefits that were important to them; they did not feel that others had benefited from the research projects more than they had; or that their health had been adversely affected because of their involvement. They also indicated that they had learned new job skills. The items which received the least endorsement related to their having received promotions at work; that they had a better understanding of their own mental illness; and that they had become better known as researchers.

These results seem to indicate that respondents did not experience any *adverse* personal outcomes as a result of their involvement in research; however, in the final comment section of the survey, some respondents indicated that they did not feel that some of the items pertained to them and that they would have preferred selecting a "not applicable" response option if one had been provided. For example, for someone who was unemployed, the items that related to employment were not applicable. Similarly, for individuals who were not receiving certain benefits, such as food stamps or social security disability income, the loss of benefits would not have been relevant to them. Consequently, these personal outcome findings may be less clear as respondents made forced choices instead of opting out of the question with a "not applicable" response.

Interpersonal Outcomes

Outcomes that related to an individual's relationships with others were assessed by a four-item scale. Those items are shown in Table 4.7. The possible range of scores for the subscale was 4-16, and the observed range was 9-16. The subscale mean was 12.6 (SD=1.70) and the scale was negatively skewed, meaning that most of the responses were grouped towards the positive end of the scale.

Table 4.7

Interpersonal Subscale Items

Scale Item	N	Mean	SD	Range	Skewness
My friends who also have mental illnesses no longer associate with me	72	3.60	.60	2-4	-1.20
I have made new friends among the researchers I work with*	70	3.21	.61	2-4	-.15
People seem to respect my opinions more*	72	3.01	.68	2-4	-.02
I have become better known as a researcher*	70	2.72	.76	1-4	-.11
Overall scale statistics	70	12.59	1.70	9-16	.06

*These items were reverse coded

From the responses, it appears that respondents were generally positive about the outcomes that related to their interpersonal relationships resulting from their involvement in research. The item that was most highly endorsed was related to

their ongoing relationships with their friends who also have mental illnesses. Their relationships with their peers did not appear to be adversely affected (i.e., discontinued) as a result of the respondents' involvement in research. Respondents also reported that they had made new friends among the researchers with whom they had worked, suggesting that participant researchers have expanded their social networks while maintaining previously established relationships.

Political Outcomes

The third subscale in the outcomes domain related to the political outcomes that respondents had experienced as a result of their involvement in research. Political outcomes were defined as those that related to the respondents' involvement with the larger community and its institutions. There were four items in this subscale that are shown in Table 4.8 (next page). The possible range of scores for this scale was 4 -16 and the observed range was 7-16. The scale mean was 13.0 (SD= 2.1).

The item that was most highly endorsed was related to respondents' willingness to advocate for others as a result of their participation in research. They were less likely to report that they had become better advocates for themselves. Respondents also indicated they believed that they had been able to positively affect other people's attitudes about working with people with mental illnesses; however, they were less optimistic about their effect on decisions about mental health policies and practices as a result of their involvement in research.

Table 4.8

Political Outcomes Subscale Items

Scale Item	N	Mean	SD	Range	Skewness
I am more willing to advocate for other people with mental illnesses*	72	3.42	.71	2-4	-.80
I have been able to positively affect other people's attitudes about working with people who have mental illnesses*	70	3.24	.60	2-4	-.15
I have affected decisions about mental health policies or practices*	70	3.17	.68	1-4	-.51
I am a better advocate for myself*	72	3.15	.73	2-4	-.24
Overall Scale statistics	70	12.98	2.10	7-16	-.347

*These items were reverse coded

What are respondents' views about the feasibility and utility of participatory research models?

Given their experiences of the research process and the outcomes that they believed were attributable to their involvement in research, to what extent did respondents endorse participatory models of research as a practice? The final section of the survey asked respondents to strongly agree, agree, disagree, or strongly disagree (with 4 being the highest positive value and 1 being the lowest) with a series of ten statements about participatory models of research. These ten items formed the Endorsement Scale as described earlier. The scale items and their descriptive statistics are shown in Table 4.9. The possible range of scores on the Endorsement Scale was 4-40 and the observed range was 24-40. The scale mean was 31.1 and the SD was 3.4, indicating that the scale is

negatively skewed and that most respondents were generally positive in their views about participatory methods of research.

Table 4.9

Endorsement Scale Items

Scale Item	N	Mean	SD	Range	Skewness
Involving people with mental illnesses improves the research process and outcomes*	70	3.83	.38	3-4	-1.78
I would recommend that others with mental illnesses participate in mental health research*	70	3.72	.45	3-4	-1.05
Funding agencies should require the involvement of people with mental illnesses in mental health research*	70	3.63	.66	1-4	-1.87
Participating in research is a good way for people who have a mental illness to influence mental health policies and practices*	70	3.51	.58	2-4	-.73
Research benefits the research professionals, but not the participant researchers	70	3.20	.67	1-4	-.55
It is not always practical or desirable to include people with mental illnesses in mental health research	70	3.17	.87	1-4	-.62
Participating in research is a good way for people to gain a better understanding of their own mental illness*	69	2.95	.79	1-4	-.47
Including people with mental illnesses in research requires extra time, effort and expense	70	2.61	.82	1-4	.19

Table 4.9 Continued

Endorsement Scale Items

Scale Item	N	Mean	SD	Range	Skewness
Professional researchers are not likely to share their power with participant researchers	70	2.57	.73	1-4	-.14
People with mental illnesses should do their own research, not just participate in research done by other professionals	70	1.92	.95	1-4	-.77
Overall Scale Statistics	70	31.14	3.40	24-40	.20

*These items were reverse coded

The majority of respondents believed that involving people with mental illnesses in mental health research improved the research process and outcomes and, based upon their experiences, they would recommend being involved in mental health research to others. They also believed that funding sources for mental health research should require the involvement of people with mental illnesses in the research process.

While respondents were less likely to agree that they personally were able to affect mental health policies and practices, as noted in the previous discussion of political outcomes, they still believed that participatory research is a good way for people to affect mental health policy and practice. They also believed that participating in research is a good way for people to gain an understanding of

their own mental illness, although they did not necessarily believe that they had personally gained new knowledge about their own illnesses.

To some extent, respondents believed that research benefits the professional researchers, but not the non-professional researchers, and that professional researchers are not likely to share their power with non-professional participants (a finding consistent with their responses to the earlier statement that regarding professional's willingness to share their power). However, these findings notwithstanding, respondents disagreed with the statement that people with mental illnesses should do their own research and not just participate in research done by professionals.

What factors contributed to respondents' characterization of their experiences?

Bivariate Pearson correlation coefficients were calculated among the scale scores to determine the factors that may be associated with respondents' views of their experience as well as their outcomes. For example, to what extent did respondents' level of experience correlate with their views about the degree to which they felt their research experiences were participatory? Similarly, were higher levels of research experience related to more positive outcomes? If the assumptions posited in the literature are correct, i.e., that participating in research has positive benefits for participant researchers, one might also expect that respondents who reported that their research experiences were more participatory would also report better outcomes and would be more likely to

endorse participatory methods of research. Table 4.10 shows the correlations among variables of interest (the extent of respondents' experience; the degree of "participatoriness" of the research experience; the personal, interpersonal, and political outcomes that respondents experienced; and the degree to which respondents endorsed participatory methods of research.)

Table 4.10

Scale Score Correlation Coefficients (N=70)

Scales	EX	P	PO	IO	POLO	E
Experience (EX)	1.00					
Participatoriness (P)	.028	1 .00				
Personal Outcomes (PO)	.096	.289*	1.00			
Interpersonal Outcome (IO)	.100	.299**	.561**	1.00		
Political Outcome (POLO)	.029	.409**	.739**	.469**	1.00	
Endorsement (E)	- .262*	.495**	.364**	.339**	.497**	1.00

* $p < .05$
** $p < .01$

According to these analyses, the degree of "participatoriness" was significantly, positively correlated with the personal ($r = .289$, $p < .05$), interpersonal ($r = .299$, $p < .01$), and political outcomes ($r = .409$, $p < .01$) reported by respondents. That is, respondents who reported higher degrees of participation also reported better outcomes. While these relationships were significantly correlated, the strength of the correlations, as determined by computation of the coefficient of determinations, was found to be in the weak ($r^2 = \leq .25$) range for seven of the ten

comparisons and to be in the moderate ($.25 < r^2 = < .64$) range in three comparisons. The strongest relationships were between personal outcomes and political outcomes ($r^2 = 55\%$) and between personal outcomes and interpersonal outcomes ($r^2 = 31\%$). Not surprisingly, however, respondents who experienced higher degrees of participation were more likely to endorse participatory methods of research (.495, $p<.01$). Respondents' levels of experience were not significantly correlated with their perceptions of the degree of "participatoriness" of their research experience or any of the outcomes that they have achieved. This finding was somewhat surprising in that one might expect that the more experienced participant researchers are, the more likely they would be full partners in the research process.

The fact that respondents' level of experience was not related to their outcomes may be reflective of the types of outcomes that were included in the respective outcomes subscales. For example, someone with ten years of research experience may not be concerned about the loss of benefits or developing new job skills, and they may already be well known as a researcher. It was somewhat surprising, however, that respondents' levels of experience were negatively correlated with their endorsement of participatory methods of research, i.e., the more experience respondents had, the less likely they were to endorse participatory methods of research ($r= -.262$, $p<.05$). Bivariate correlations also were computed to determine if the involvement of more than one person with a mental illness in the research process or the mandate to

include persons with mental illnesses in the research was associated with the respondent's perceptions of how participatory the research experience might have been. Also, did the fact that inclusion was required in any way correlate to more than one person with a mental illness being included in the research process? As seen in Table 4.11, findings from these correlations indicated that neither the involvement of others nor the mandate for the inclusion of others was related to the "participatoriness" of the experiences reported by respondents. However, the mandate for the inclusion of people with mental illnesses in the research process was positively and significantly correlated with other people with mental illnesses being involved ($r=.927$, $p< .01$). The strength of the correlation was also in the strong range ($r^2 = 86\%$).

Table 4.11

Correlation Coefficients for Mandated Inclusion, the Inclusion of Others and Perceptions of Participatoriness

Item/Scale	Others with mental illnesses also participated	Inclusion was mandated	Participatoriness of experience
Others with mental illnesses also participated	1.00		
Inclusion was mandated	.927**	1.00	
Participatoriness of experience	-.171	.22	1.00

***p< .01*

This means that when the inclusion of people with mental illnesses was mandated, it was much more likely that more than one person would be included in the process.

To determine if the research environment, (i.e. the type of host agency for the research, the funding source, or the mandate for inclusion) was related to respondents' perceptions of the "participatoriness" of their experience or their outcomes, one way Analysis of Variance (ANOVAs) were computed. There was no significant relationship found between the type of host agency and the degree to which respondents believed that their experiences were participatory $F(3, 67) = 1.77$, p=ns; the type of host agency and respondents' personal outcomes $F(3, 65) = 2.13$, p=ns; the type of host agency and respondents' interpersonal outcomes $F(3, 65) = .83$, p=ns; or the type of host agency and respondents' political outcomes $F(3, 65) = 1.40$; p=ns. Nor were there any significant relationships found between the type of funding source and the respondents' views of the participatoriness of their experiences $F(2, 68) = 1.17$, p=ns; the type of funding agency and respondents' personal outcomes $F(2, 66) = .75$, p=ns; the type of funding agency and respondents' interpersonal outcomes $F(2, 66) = .20$, p=ns; or the type of funding agency and respondents' political outcomes $F(2, 66) = 1.41$; p=ns. Also there were no significant relationships found between the mandate to include consumers/survivors in the research process and respondents' views of the participatoriness of their experiences $F(2, 64) = .62$, p=ns; the mandate and respondents' personal outcomes $F(2, 63) = .37$, p=ns; the mandate and respondents' interpersonal outcomes $F(2, 63) = .65$, p=ns; or the mandate and respondents' political outcomes $F(2, 63) = .10$, p=ns.

The results, as summarized in Tables 4.12 and 4.13, indicate that there were no significant associations between the research environment and the degree to which respondents felt their experiences were participatory or the outcomes they achieved.

Table 4.12

Relationship Between Research Environment and Participatoriness

One Way ANOVAs	Participatoriness			
	N	$\bar{X}$	SD	Sig.
Host Agency				.160
Government	18	78.7	10.1	
University	22	75.6	12.2	
Private agency	10	81.2	12.2	
Service Provider	21	83.6	12.1	
Funding Source				.889
Government	55	79.3	12.7	
Foundation	14	79.7	8.8	
Private sources	2	83.5	12.0	
Mandate for Inclusion				.540
No	12	77.3	15.0	
Sometimes	26	78.2	9.4	
Yes	29	81.2	12.9	

Table 4.13

Relationship Between Research Environment and Outcomes

One Way ANOVAs	Personal Outcomes				Interpersonal Outcomes				Political Outcomes			
	N	$\bar{X}$	SD	Sig.	N	$\bar{X}$	SD	Sig.	N	$\bar{X}$	SD	Sig.
Host Agency				.105				.483				.483
Government	18	37.2	3.9		18	12.5	1.7		18	13.2	2.1	
University	21	35.4	3.7		21	12.2	1.6		21	12.4	1.7	
Private agency	9	39.2	5.3		9	12.4	2.1		9	14.0	1.4	
Service provider	21	38.1	5.0		21	13.0	1.7		21	13.1	2.5	
Funding Source				.475				.818				.252
Government	53	36.9	4.1		53	12.5	1.5		53	12.8	2.0	
Foundation	14	38.5	5.1		14	12.8	2.3		14	13.9	1.9	
Private sources	2	36.0	11.3		2	13.0	2.8		2	13.0	4.2	
Mandate for Inclusion				.690				.527				.903
No	11	37.7	5.9		11	12.3	2.1		11	12.9	2.6	
Sometimes	26	37.6	4.1		26	12.8	1.7		26	13.0	2.0	
Yes	29	36.6	4.6		29	12.3	1.5		29	13.0	2.1	

End-of-survey Comments

At the end of the survey, respondents were provided the option of adding any comments that they chose to make. Slightly more than half (38) of the 72 individuals who completed the entire survey responded to the open-ended question, and a content analysis was conducted on their text entries. Four major themes/categories emerged from that analysis: 1) comments on the survey itself (positive and negative); 2) positive views about participatory models of research; 3) negative views of participatory models of research; and 4) outcomes (positive and negative) experienced by the respondent. Slightly more than a third of the

respondents made comments about the survey itself. Another third of the responses related to the outcomes (both positive and negative) respondents had experienced as a result of participating in research. The remaining responses were classified as either being positive or negative comments about participatory research, but the majority of them were positive. Each of these themes is described in more detail below.

Comments on the survey.

A number of the responses classified in this category reflected respondents' concerns that some of the questions did not relate to them or their situations and that there was no "not applicable" response option for them to select. As one respondent wrote, "...several of your questions were premised on the assumption that I – the respondent -- was a non-professional working with professionals, since no "not applicable" option was offered and it was required that every item get a response, some of those particular responses were not valid." Another commented "some of the strongly agree/disagree questions did not apply to me, but I was forced to answer them because I couldn't move forward without answering them" and a third respondent wrote, "some of the questions posed in this survey do not pertain to all individuals. There should be a check box for items that are non applicable [sic]." The fact that several comments were made about the relevancy of some of the questions may be indicative of the range or variation in the types of individuals who may have responded to this survey. As noted earlier, the numbers of years of research

experience varied with almost 37% of respondents reporting ten or more years of experience and almost 57% reporting fewer than four years of experience.

A number of other respondents voiced their disagreement with the language used in the survey and/or the underlying assumptions for the study. The following comments illustrate their concerns. "This research is faulted [sic] as it places mental illness as a condition rather than a diagnosis....Some of the questions perpetuate stereotypes about people who are deemed to have a psychiatric disability." Another respondent wrote, "Many questions seem to assume that I am somehow 'disabled' by my psychiatric history whereas I personally feel greatly 'enabled' by it, and indeed is [sic] a major positive factor in the research I do." Yet another person said, "Just an issue with two questions...Don't these questions infer that the respondent is still suffering from a mental illness? What about those of us who consider ourselves fully recovered?"

It is also important to note that some of the respondents who had voiced their concerns about the survey subsequently e-mailed the investigator directly. Their e-mails were reflective of their earlier written comments but were generally more detailed and offered greater explanation of their written remarks. All e-mails were acknowledged and were considered in the content analyses conducted on the text responses.

There were only a few text responses that could be categorized as positive comments about the survey. Respondent statements generally expressed interest in having access to the results of the study and were

supportive of the undertaking as reflected in the following quote: "My responses on the negative side do not reflect discrimination or unique treatment due to my diagnosis, everyone I work w/ is a family member or has their own lived experience. Great study!" Another wrote "Please let me know the results of your work – I am very interested and glad you are doing this work as it has needed to be done." A third wrote "...can I have a copy of the results? It is very relevant to what I do."

The fact that the majority of responses within this theme were critical of the survey and that some respondents were motivated to communicate with the investigator further suggests that the issues covered by this survey are highly personal and that they triggered strong reactions among some respondents. Specifically, many of the remarks seem to reflect that people with mental illnesses have different ways in which they define their illnesses and their relationship to it.

Positive Views of Participatory Research.

Several responses (ten) were classified as endorsement of participatory research approaches. They included such statements as "I think that participation in research by persons with psychiatric disorders can be empowering. Researchers need to be willing to share their power and knowledge." Another respondent wrote, "Every aspect of mental health research, policy and service development should include consumers as equal participant and only projects that do should be considered valid and/or relevant to

governments or policy makers." Another added, "To emphasize including the mentally ill in ALL research on mental illness. I know that with some it is difficult for professionals, but they should open their doors wide to those like myself that are fully able to participate."

While these comments endorse participatory methods of research, they stipulate that participatory methods *should be* employed, but do not indicate that they believe that they *are,* in fact, being employed. For example, as one comment suggests, "...We must challenge the present research done by those who hold too much power..."

Negative Views of Participatory Research.

Other comments (seven) were less positive about participatory research methods, as exemplified by the following statements made by respondents. "Common practice now is to use consumers as an advisory committee. Sometimes we only listen to reports, meaningless. We cannot get researchers to change anything. We are asked to be involved too late." "...Some of the decisions about the research were made before I was consulted, so participation was not full..." "In my attendance at professional research meetings however [sic] I have found the research community to be extraordinarily bigoted about mental illnesses and indeed very ignorant about the people they research." Another wrote "I have found that, although I have a strong interest in mental health services research, it has been difficult for me to engage other colleagues where I work to develop research activities and find funding on mental health

topics...I understand that I'm dealing with a chronic illness, but not everyone to whom I disclose my illness does understand this. Sometimes I think my colleagues will be more understanding (than they really are) regarding my occasional need for 'accommodations' such as flexible work hours and short term disability leave."

These findings seem to suggest that even when participatory methods are used, they are not always authentic and that mental health participant researchers still face discriminatory attitudes.

Outcomes Related to Research Experiences.

Notwithstanding the earlier comments, the majority of responses were definite about the benefits they had obtained as a result of their experiences in research. For example, "Working as a research assistant was a very positive experience for me and helped me understand my own issues. The professionals gave me the respect I needed to get through some rough times in my personal life." Another respondent wrote "I have loved being involved in this research project and it has led to many other great opportunities for me." Also, "Because of my participation in research, I am being encouraged to pursue graduate degrees at both the masters and Ph.D. levels..." Only a few remarks suggested less positive outcomes, as illustrated in the comment by one respondent, "...because I was on SSI I could not accept any stipend money without losing my support. Money needed, [sic] but I couldn't use it benefit." Another respondent

noted that he/she had put his/her whole life into projects, implying that it was less than beneficial.

Summary

Chapter Four represents the findings from the survey's quantitative responses as well as qualitative comments made by respondents. Descriptive statistics including frequencies and means as well as bivariate Pearson correlations and one-way ANOVAs between the variables of interest that respond to the study's research questions were also presented.

The findings revealed that the people who responded to this survey were more likely to be white, female, and non-Hispanic. Most respondents were over the age of 40 and had incomes of less than $40,000 per year. The majority of respondents reported being unemployed, but almost half (46%) were paid for the work that they did as researchers. More than half of the individuals reported having completed post-secondary degrees, seven people (9%) had Ph.D. degrees. There were 28 (37%) experienced researchers (10+ years in research) in this survey sample, but 43.5% of individuals had four year or less of experience in research. Most of the research reportedly was conducted in either universities or service-providing agencies, with most of the funding for research coming from the government. When participating in research, the majority of respondents indicated that they were known to have a personal experience with a mental illness, and there was generally more than one person with a mental illness involved in the research. Respondents reported that in most instances,

the participation of persons with mental illnesses in the research was required and that requirement was found to be positively correlated with more than one person being involved. One-way ANOVAs revealed no significant relationships between the research environment and either the participatoriness of the experience or the outcomes they achieved.

Respondents generally reported that they found their experiences to be participatory and that they had experienced some positive personal, interpersonal, and political changes in their lives as a result of participating in research. Respondent outcomes were found to be positively correlated with the extent to which they perceived their research experiences to be participatory; however, those positive correlations were not strong. Further, the extent of reported participatoriness of the research experiences as well as the reported positive outcomes of respondents, were also positively associated with their endorsement of participatory methods of research. However, the extent of the respondents' experience was not associated with either their perceptions of the degree of participatoriness of their experiences or their reported outcomes. Somewhat surprising was the finding that the more experience respondents had, the less likely they were to endorse participatory methods.

From the qualitative comments provided by respondents, it is clear that many view their mental illness as the life experience that has helped prepare them to do research. They also related to their experiences with family members who have/had mental illnesses as being instrumental in helping them to become

involved in mental health research. It is also clear, given the critical tenor of many of the respondents' comments and the fact that some were motivated to make direct contact with the investigator, that language, e.g., the term "mental illness," is an important and sensitive subject to people who have experienced such disorders. It is also apparent that the persons who responded to this survey viewed their personal experiences with a mental illness in many different ways, with some expressing more positive views of their experiences and others indicating that they do not define themselves or their experiences in terms of their illness.

CHAPTER FIVE

INTERPRETATION, LIMITATIONS, AND CONCLUSIONS

A dominant theme reflected in the participatory research literature (most often written by research professionals) is that the experience of participating in research creates new knowledge and empowers the individuals who are involved in the process (Beresford and Evans, 1999b; Dullea and Mullender,1999; Wells et al. 2006). As discussed in Chapter Two, participant researchers' personal, interpersonal, and political lives presumably are positively changed as a result of their involvement. However, there are few accounts by participant researchers themselves about their experiences and outcomes (Morrell-Bellai and Boydell, 1994; Telford & Faulkner, 2004). This exploratory study was designed to obtain the perspectives of mental health consumers/survivors regarding their experiences as participant researchers, how *they* viewed their experiences and whether or not *they* believed that, as a result of participating in research, their lives were changed. This study also sought to gain insight regarding the elements of the research process which were associated with their reported experiences. The overall goal of this inquiry was to gain insight into the processes of participatory research so that new understanding might lead to improved use of these models.

Chapter Three described the methods by which each of the research questions were addressed. Data were collected from individuals who had, or had in the past, a mental illness and indicated that they had participated in research

in some role other than as a respondent or subject. Respondents were recruited using a wide variety of methods, often through the assistance of well-known consumer/survivor researchers as well as other professional researchers. Respondents were invited to share their research-related experiences by answering a series of structured, close-ended questions that were developed using the existing literature on empowerment and participatory research. Survey items were grouped into six domains of interest that included: the extent of their research experience and their formal credentials; the research environment; the extent to which they believed their experiences were participatory; the personal, interpersonal, and political outcomes they achieved; the extent to which respondents endorsed participatory models of research; and their demographic characteristics. Five scales were created that would yield composite scores for: 1) the extent to which respondents considered their research experiences to be participatory; 2) their personal outcomes; 3) their interpersonal outcomes; 4) their political outcomes; and 5) the degree to which respondents endorsed participatory methods of research. Respondents were also offered the opportunity to provide additional written comments at the end of the survey. Descriptive statistics and Pearson correlation coefficients were computed for the quantitative data, and text responses were analyzed by conducting content analyses.

Chapter Four described the findings from the data and the results of the analytic methods used. The majority of individuals who responded to the survey

were white, non-Hispanic females over the age of 40 with incomes less than $40,000 per year. The majority of respondents had post-secondary education degrees, and more than a third had ten years or more of research experience. However, 43% reported having fewer than two years of research experience. Respondents also reported having fulfilled a variety of roles in their research experiences.

Correlational analyses conducted among the scales of interest showed positive, significant associations between the extent of respondents' perceived participatoriness of their experience and the outcomes that they had achieved. Also, there were positive, significant relationships found between the participatoriness of respondents' experiences, respondents' positive outcomes, and their endorsement of participatory methods of research.

In this chapter, three topics related to the results are addressed: interpretation of the study's findings; limitations related to the study methods and measurement; and implications and recommendations related to future social work research.

Interpretation of Findings

There were four primary questions that guided this study:

1. To what degree have participant researchers who have a mental illness (presently or in the past) felt they were meaningfully involved in the research process?
2. What factors contributed to their characterization of their experiences?

3. What is the relationship of their participation in research to their personal, interpersonal, and political lives?
4. What are participant researchers' views about the feasibility and utility of participatory research models?

These questions provided the framework for the inquiry that would potentially yield a better understanding of the experiences of participant researchers who had a mental illness (presently or in the past) during the research process as well as their outcomes from their participation. The final question related to their insiders' view of participatory methods of research. Due to their first-hand experience in research, their views about the feasibility and utility of these methods represent an important perspective.

To what degree have participant researchers felt they were meaningfully involved in the research process?

The assumptions underlying this question are that there are variations in the extent to which participants are involved in research and that there are qualitative differences in participant researchers' views of their experiences. These premises were explicated in Chapter Two, which described the varying levels of involvement discussed in the literature in terms of participant researchers' control of and actual engagement in the process (Hick, 1997). Given that participant researchers may have experienced varying levels of involvement, it is reasonable to assume that there may be qualitative differences in how they view their participation. One might also expect that the variations in

their experiences may be differentially related to their outcomes and whether or not they would have favorable views regarding participatory methods of research.

The findings from this study showed that the majority of the respondents felt that their research experiences were, in fact, participatory as defined for purposes of this study. They felt that they were treated with respect, that it was usually safe for them to express their opinions, and that they were adequately prepared to participate. Thus, participant researchers generally felt that the socio-emotional aspects of their involvement were positive, a finding that is consistent with the views of other participant researchers found in the literature. (Hanley, 2005, Morrell-Bellai and Boydell 1994; Rose, Ford, Lindley, Gawith, & the KCW Mental Health Monitoring Users' Group, 1998; Woodside, Cikalo, and Pawlick, 1995) However, they were less positive about their instrumental roles in the research process, i.e., they reported that they were not always asked to participate in all phases of the research and were not often asked to assume more responsibilities. They also did not believe that they had an equal role in decision-making or that professional researchers were willing to share their power. These findings suggest that while participant researchers were treated respectfully, they may have been less than equal partners in the process.

It is possible, if not likely, that the respondents in this study may have been involved in research projects that did not use participatory methods of research where there was shared ownership of the process. Perhaps the models in which respondents were most often engaged were more traditional in

their approach. Given that the traditional paradigm of research has been that the professional is considered to be the "expert" and is most often in control of the process, it is not surprising that participant researchers in this study did not appear to be fully integrated into research projects.

An important observation offered by one of the research consultants to this study was that participant researchers are often engaged in projects to carry out a particular role, such as conducting interviews in the data collection phase, serving as advisors, or entering data. Consequently, they might not expect to have an equal role in decision-making or be asked to participate in all phases of research. While this may be true, it begs the question about whether their limited role constitutes involvement in authentic participatory models of research or whether they were simply employed to do a specific job and their life experiences as consumers/survivors were secondary, if considered at all. Furthermore, if, as it was found in this study, consumer/survivor participation in mental health research was often required, it may be that their involvement was related to the mandate rather than commitment to the model.

As indicated by the findings of this study, participant researchers fulfilled a variety of roles in the process, from serving as director of a research project to entering data. What was less clear, however, was the extent to which the life experiences of these respondents helped shape the research. After all, in participatory research it is their perspectives derived from their life experiences that are part of the rationale for their inclusion. If they were relegated to

circumscribed roles that simply fulfilled a functional need, one might argue that their inclusion did not really constitute participatory research, or at least their involvement represented a form of participatory research that only marginally met the definition.

That is not to say that there are no benefits to be achieved as a result of having a limited role in the process. Learning new job skills, an outcome reported by the individuals in this study, is an important accomplishment that could potentially lead to new opportunities. However, skill development is only one aspect of the empowerment of participants that was envisioned by the proponents of participatory research. Enhanced self-confidence, the ability to make positive life changes, and improved self-advocacy are among the elements that constitute empowerment, according to the consumer/survivors who defined the term (Rogers et al., 1999).

Participatory research is predicated upon the participation of individuals who have a stake in the matters under study. Ostensibly, participants are involved because they are experts by virtue of their experience, i.e., they bring a unique insiders' view to the research. It is a process that is directed towards social action and change; it involves collaboration, co-learning, and the sharing of power. It is inclusive. One of its explicit goals is to empower the individuals who participate in order to facilitate their own problem-solving. In addition to the benefits that are realized by participants, its supporters assert that through the participatory research process, the science is improved, the issues being studied

will have more real world relevance, and they will more likely lead to change. (Cleary, Walter, and Escott, 2006; Danley and Ellison, 1999; Faulkner and Thomas, 2002; Halliday, 2003)

As discussed in Chapter Two, there are wide variations in the way participatory research methods are implemented. Participatory research can be conceptualized along a continuum, from participants having little involvement and control (which is more typical of traditional research methods with professionals in charge) to their being fully involved and controlling the process (a model more characteristic of participatory methods or of consumer/survivor directed research). It is likely that in those instances where participant researchers played only a limited role, the research model was more consistent with the traditional research paradigm.

What is the relationship of participation in research to their personal, interpersonal, and political lives?

Respondents were asked about the degree to which their participation in research had resulted in changes in their personal, interpersonal, and political lives. The mean scores on the three outcomes subscales indicate that respondents generally believed that their research participation resulted in some positive changes in their lives. A number of respondents also provided positive comments about what they had gained through their research experience, as reflected in such remarks as: "Because of my participation in research, I am being encouraged to pursue graduate degrees..." and "I have learned many

lessons about working with a mental illness..." Findings from both the quantitative analyses and the qualitative data in this study were consistent and supported the views of both professionals and participant researchers found in the literature. (Beresford and Evans, 1999; Elliott, Watson, and Harries, 2002: Morrell-Bellai and Boydell, 1994; Reeve, Cornell, D'Costa, Janzen, & Ochocka, 2002)

However, notwithstanding the generally positive outcomes reflected by the mean score on the personal outcomes subscale, the most strongly endorsed items in the scale were those that reflected respondents' beliefs that they had not experienced any adverse outcomes because of their involvement in research (e.g., losing benefits or that their health was adversely affected), which is different than strongly endorsing positive outcomes. It is possible that there were only limited personal benefits achieved; however, respondents' reactions to the negatively worded items may have been, in part, an artifact of measurement. King, (n.d.) and others (Schriesheim and Esenback,1995) have described a phenomenon where respondents may not recognize the reversal or negatively stated survey items when they are presented with positively worded items and consequently may inadvertently select the wrong response option. The extent to which this may have been a factor in this study is unclear but must be considered in the interpretation of these data.

Aside from reporting that they had learned new job skills, respondents were less likely to have reported benefiting from their research experiences

through offers of additional work or increases in salary or promotions. They also did not believe that they had become better known as researchers. If they had, they might have been more sought after to do additional work. Thus, while respondents may not have experienced any adverse personal outcomes, they may not have benefited in more tangible ways, such as through increases in salary/promotions or other job offers. It is important to note, however, that more than half of the respondents reported that they were unemployed at the time they completed the survey; therefore, the statements regarding salary increases/promotions may not have been relevant to them.

In terms of changes in respondents' interpersonal relationships, the most strongly endorsed items were that they continued to associate with their network of friends who also had mental illnesses and that they made new friends among the researchers they had worked with. This suggests that consumer/survivor researchers maintained their ties to their peers as they engaged in research activities with other professionals and that rather than replacing their previous relationships; they have expanded their social networks. Respondents did not believe, however, that their involvement in research had resulted in either their opinions being more respected or, as noted earlier, that they had become better known as researchers, even though a number of them reported that they had presented research results at conferences and workshops. One might speculate that if their roles were circumscribed in the projects in which they were involved, as one study consultant has suggested, they might not be as visible in the

process. They may not have received the recognition or notoriety that other professionals often enjoy. As noted by Hodges (2005) in his efforts to determine if consumer/survivors were being included in research teams, only 16 of the 250 (6%) articles he had selected for his study explicitly mentioned that mental health consumer/survivors had been involved at some level in the research. While his findings may reflect the fact that consumers/survivors were not actually included in the process, they may also indicate that they were not acknowledged as being involved.

The third life domain that respondents were asked to address related to the changes they had made in their political lives as a result of participating in research. The oft-cited premise in the literature is that people who participate in research are empowered to make changes in the political structures and policies that affect them (Freire, 2000; Sohng, 1998). Respondents in this study were generally positive about some of the political outcomes they had achieved through their research experiences. They felt that they were more willing to advocate for others who had mental illnesses and believed that they had positively affected other peoples' attitudes about working with people who have mental illnesses. However, they were less positive about their being a better advocate for themselves and less optimistic about their impact on decisions about mental health policies or practices.

The fact that respondents did not believe they had been able to influence mental health policies or practices is not surprising, as policies and practice are

difficult to change. The Institute of Medicine (2001) has estimated that it takes between 15 and 20 years for research to affect practice. The President's New Freedom Commission on Mental Health (2003) also noted that while research often yields important advances, the findings often "languish for years" before they influence practice or policy. Assuming that is true, it is unlikely that respondents have had much opportunity to see change occur as a consequence of the research in which they were involved. Also, the influence of any one individual in the mental health research enterprise is often obscure, particularly if they were not in the position of directing or controlling the process. Respondents may not have seen the direct results of their personal contributions to the research process. As Telford and Faulkner have pointed out (2004) "...the capacity to bring about change may not be in the hands of the researchers or collaborators; other external agencies, resources and political motives may militate against it" (p. 552).

What factors contributed to respondents' characterization of their research experiences?

There were positive, significant relationships found between respondents' views about the extent to which their research experiences were participatory and the positive changes in their personal, interpersonal, and political lives that were derived from those experiences. Although the magnitude of the correlations was not very strong, these findings suggest that the extent or the degree of "participatoriness" of the research experience i.e., the extent to which

individuals perceived that they are accepted as part of the research process, was meaningfully associated with the outcomes they achieved. The fact that they felt respected and valued as research colleagues, as indicated by their responses on the "participatoriness" scale, suggests that the relationship aspects of the research process are important factors when assessing the outcomes achieved. Although respondents may have been engaged in more traditional models of research where they were less likely to have had an equal role in decision making or to have been included in all aspects of the research, those factors appear to be less important in their achievement of positive outcomes.

This finding is consistent with earlier work by this investigator in which the characterization of the concept of participation by consumer/survivors in the literature was found largely determined to be in terms of their interpersonal relationships (Robinson, 2000). Professionals were more likely to describe the need for training or adequate compensation for participant researchers as important considerations in their involvement, while consumer/survivors were more likely to discuss their participation in terms of the interpersonal relationships they had with the professional researchers.

Among the associations that were tested, the stronger relationships were found between personal outcomes and political outcomes and between personal outcomes and interpersonal outcomes. While these were still moderate correlations, they suggest that these life domains may interact. As changes occur in the personal domain of someone's life, there also may be changes in the

interpersonal and political aspects of their lives. For example, the degree to which an individual gains new self-confidence is likely to affect their interpersonal relationships. Similarly, an enhanced sense of personal efficacy may also motivate a person to become more politically assertive. While these data do not provide sufficient justification to make claims of causality, the direction of the findings is consistent with what might be expected, based upon the theoretical framework of empowerment. Empowered individuals experience enhanced self-esteem, have new confidence in their abilities, and develop a sense of self-efficacy that enables them to make changes in their interpersonal lives and to take political action (Freire, 2000; Sohng, 1998;). The findings from these data are consistent with this view of empowerment and the oft-cited proposition that participation in research is an empowering experience for individuals.

There were no significant associations found between the organizational environment (i.e., the type of agency in which the research was conducted, the funding source for the research, or whether or not there were requirements that people with mental illnesses be involved) and either the extent to which respondents felt that their experiences were participatory or the outcomes that they achieved. This suggests that the environment in which research is conducted is not a constraint in the achievement of positive outcomes for participant researchers, but it also indicates that it is not a contributory factor either. In this study, universities were identified as one of the primary organizations in which respondents had participated in research. Because

research is typically a part of a university's mission, the university environment could be more conducive to the practice of participatory methods of research. However, this would require university researchers to share their power and the control of the research process, a step that traditionally prepared researchers may find hard to make.

There was one significant finding related to the research environment. Where there were requirements for people with mental illnesses to be included in the research, it was more likely that more than one person would be involved. This may indicate an important role that funding or host agencies can play in expanding the numbers of individuals involved in research. For example, the National Institute of Mental Health recently issued a call for proposals that explicitly require the use of participatory research methods (National Institute of Health, 2006). While such requirement trends may hold promise for expanding consumer/survivor participation in research, they do not ensure that participant involvement will be meaningful to the process or to them.

What are respondents' views about the feasibility and utility of participatory research models?

Given respondents' positive views of their own experience in research and the benefits they believe they received as a result of their participation, one might expect that they would endorse participatory methods of research. The findings from this study support that assumption; most respondents expressed positive views about participatory research methods. They indicated that involving

people with mental illnesses in research not only improved the science but also benefited them in the process. They recommended that, based upon their own experiences, other people with mental illnesses should participate in mental health research and that funding agencies should require that consumers/survivors be involved. While respondents were less optimistic about their own ability to influence change in mental health policies, they still supported the idea that participation in research was a way for people to affect change. Similarly, although most respondents did not feel that they had personally learned more about their own mental illnesses through their participation in mental health research, they endorsed the idea that participating in mental health research was a good way to gain a better understanding of one's own mental illness. Despite indications that respondents still believe that professional researchers are not likely to share their power, they did not suggest that people with mental illnesses should do their own research rather than participate with other professional researchers.

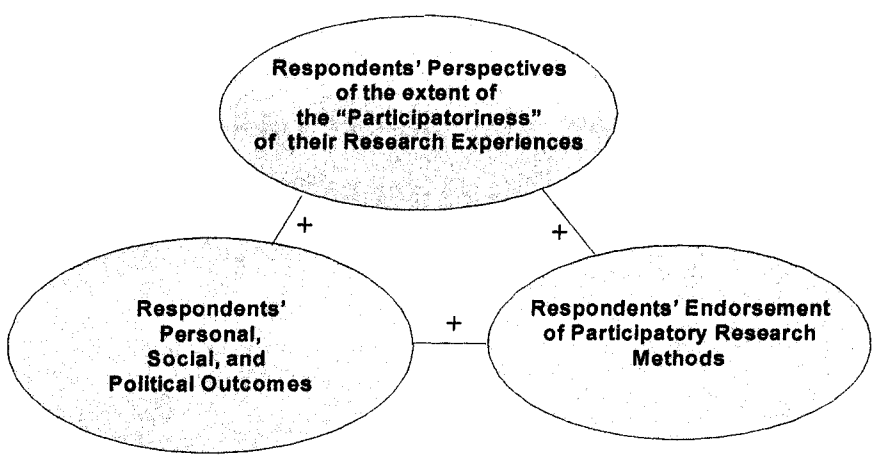
The positive endorsement of participatory methods of research is reflective of the "Nothing about us, without us" (Charlton, 2000) mantra of many mental heath consumer/survivors. Whether or not they have personally benefited from participating in research, they support the concept that mental health consumer/survivors should be involved in research that is about them. While these study findings suggest that, in reality, there are still limitations in the ways that participatory research is carried out and there may be limits to the

outcomes that are achieved, many respondents still viewed it as a worthwhile endeavor.

The findings from this study are summarized in Figure 5.1, which depicts the associations among the domains that were found to be correlated. The links do not indicate causality but rather represent the positive, significant relationships that were found among the variables of interest. The perceived participatoriness of the consumer/survivors' research experience is positively associated with the outcomes they achieve and their endorsement of participatory methods of research.

Figure 5.1

Associations Among Relevant Variables



The research environment and the respondents' levels of research experience were not linked with either the respondent outcomes or their

endorsement of participatory research, with one exception. The extent of the respondent's research experience was found to be significantly, *negatively* associated with their views of participatory research methods. It appears that the more research experience respondents had, the less likely they were to positively endorse participatory methods of research. It may be that more experienced respondents were more likely to be engaged in their own research or had a different view or understanding of participatory research. They may have already transitioned into the role of professional researcher. As one respondent pointed out, "My research experience has been as a professional researcher, e.g., as principal investigator...I don't know if my experience in fact counts as participatory action research."

Study Limitations

Although there were important insights derived from this study, there were a number of methodological limitations which should be noted. They are addressed in the following section.

Sample Identification and Recruitment

This study focused on a narrowly defined population, i.e., individuals who have participated in mental health research in some capacity or role other than as a respondent or subject and who have or have had a mental illness. Unfortunately, there was no way to estimate the size of the population of mental health consumer/survivor researchers or their characteristics. Consequently, it is not possible to assess the representativeness of the study sample and or to

generalize the findings from this study. Also, the study sample was comprised predominately of white, non-Hispanic females, most of whom had obtained post-secondary degrees, but due to the lack of information about this population of researchers, there was no way to determine if this sample was, in any way, representative of the larger population of mental health consumer/survivor researchers. The findings from this study offer some insight into the characteristics of consumer/survivors researchers, but it will take additional studies involving this population to learn more about them.

People with mental illnesses often face discrimination as a result of the pejorative views that others may have about such disorders and, as a consequence, may not be willing to publicly disclose the fact that they have/had a mental illness (President's Freedom Commission, 2003; Corrigan, 2004; Wahl, 1999). Those individuals are not likely to have chosen to participate in this study, even though they may have been given the opportunity and there were assurances and safeguards of confidentiality in place. As a result, the study sample may be biased because there could be significant differences between those who chose to participate in this study and those who refused to do so. This issue is not easily resolved, given the ongoing problems of stigma and prejudice that are associated with mental illnesses. Individuals will continue to be reluctant to disclose their mental illnesses as long as they face discrimination because of their disorders. Consequently, protection of confidentiality will be of critical importance in any future efforts to learn more about consumer/survivor

researchers. Perhaps by involving participant researchers who have had similar personal experiences, others may be more willing to participate.

In order to recruit as many respondents as possible, there were no a priori standards or definitions of mental illness established for this study; respondents self-determined whether or not they had a mental illness. As a result, there were likely to be wide variations in the types, intensity, and currency of the disorders represented by the individuals in the sample. (Evidence of this variability was reflected in some of the comments made by respondents.) However, notwithstanding the potential source of bias that resulted from the wide variation of mental disorders that may have been represented by the individuals in this study, it is unlikely that a reasonable standard definition of mental illness could or should be imposed. Based upon comments made by some respondents and one of the consultants to this study, the term "mental illness" is not very useful; respondents did not necessarily see themselves in terms of their illnesses. To the extent that this is true, this will present a challenge for any future research that seeks to learn more about the views of individuals with mental illnesses and their involvement in research. By including consumer/survivor researchers in future research efforts, the use of language could be better informed by their experiences, insiders' knowledge, and opinions.

There was also no standard definition of research, which allowed for wide variation in how people may have interpreted the work that they did as consistent with the broad concept of research. How these variations in interpretation may

have biased the study sample or otherwise influenced the study outcomes is undeterminable. Other researchers wanting to study the issues related to participation in research may consider establishing a clearer definition of what is intended by the term "research" to better ensure a more consistent frame of reference for participants.

Recruitment of respondents for this study was conducted primarily in the United States, yet wide distribution of recruitment materials was made possible via the Web. As a result, individuals from Canada, England, and Australia also participated in this study, as indicated by their correspondence with the investigator. Respondents from other countries may have had very different experiences of participatory research than their U.S. counterparts, but the extent to which these cultural differences may have influenced the outcomes of this study is also unknown. Any future effort to study participatory research as it is practiced in the United States should consider using more direct approaches in the recruitment of respondents rather than the broad marketing strategies that were used in this study.

The snowball sampling methods used to recruit respondents, i.e., asking respondents to forward copies of the survey or an e-mail attachment to other participant researchers, reduced the investigator's control over the sample selection and the ability to follow up with non-responders. A second strategy employed to recruit respondents involved enlisting the assistance of other professionals who were known to have worked with consumer participant

researchers of interest for this study by asking them to forward survey materials to potential respondents. There was no way of knowing, in either approach, if surveys/e-mails were actually forwarded to others, or if they were forwarded, how many others may have received them. The reliance upon others to help recruit respondents made it difficult to determine the adequacy of the number of responses received, and it was unclear how the variability in recruitment methods may have also biased this study sample. As noted earlier, more direct approaches in locating potential respondents would have been preferable. Direct contact would have provided greater opportunity to follow-up with non-responders and allowed for better interpretation of response rates. However, the feasibility of such an approach will continue to be problematic as long as consumer/survivor participant researchers are less visible in the literature and in the research practice.

Instrumentation

The survey instrument used in this study was developed specifically for this study. Even though survey items were developed from relevant first person and professional accounts in the literature, and drafts of the instrument were reviewed by the study consultants and subsequently field-tested, the use of instrumentation with known psychometric properties that assessed the domains of interest in this study would have been preferable. The study also was limited to the specific items on the survey instrument and consequently may not have adequately captured the true complexity of respondents' experiences of

participatory research, as indicated by the fact that over half of the respondents chose to make additional comments at the completion of the survey and others were motivated to follow-up by corresponding with the investigator directly. The use of a quantitative approach limits the amount of detail that can be obtained but does provide for a broader range of consumer/survivor researcher perspectives. However, in order to gain a deeper understanding of the experiences and perspectives of participant researchers, the use of more qualitative methods, such as case studies and/or participant observation, would be more appropriate and would serve to complement the broader view obtained through more quantitative approaches.

Some respondents indicated through their written comments that there were items that did not apply to them or their situations, and that there was no "not applicable" response option for them to select, which limited them to the response options provided. While including a non-applicable response option in some questions might have provided additional information about the respondents, the fact that it wasn't included prompted some respondents to provide additional details about themselves through their written comments. Also, most items on the Web-based survey were constructed in such a way that required individuals to respond to each item before continuing to the next. In the first two sections, response options included the "I choose not to answer this question" statement that would allow them to essentially skip a question without exiting the survey. Despite having that option available, some respondents may

have disliked having to make forced choices on questions with which they either disagreed or that they believed did not apply to them. This may have resulted in some respondents exiting the survey before completing it, as indicated by the attrition figures noted in Chapter Three. Also, some individuals indicated that because they had to make a forced choice on items that were not applicable to them, their responses did not accurately reflect their situation or views. Adding a "not applicable" category to all scales and a neutral response category on the 4-point scales might have improved the survey completion rate as well as any inaccurate responses.

Procedures

At the outset of this study, four consumer/survivor researchers were asked if they would help guide the research by reviewing drafts of the survey, assisting with recruitment, and providing their insights with respect to data interpretation. They were also asked to journal their experiences with this study. They volunteered to participate without remuneration, but during the course of the study, only one remained actively involved. Also, she indicated at the end of the study that she had not made notes about her experiences as a consultant to this project. Given the extended period of time during which this research was conducted, more frequent communication with the consultants and payment for their time might have helped to sustain their participation and would likely have resulted in a more reciprocal relationship. However, the consultants also had their own life priorities and, understandably, were not always available when

needed. Differing priorities and expectations among the research partners, time constraints, limited resources and the lack of communication are the realities of attempting to practice more participatory approaches to research

While this study did not purport to be conducted as participatory research and the involvement of the consultants was limited, they provided invaluable insights. Clearly, this study would have been additionally enhanced through their more active involvement. If such a study were to be undertaken in the future, a more participatory approach would be desirable.

Data Analysis

This was a cross-sectional, exploratory study designed to obtain the views of participant researchers' experiences regarding their outcomes resulting from their involvement in research. Rather than pose a hypothesis, the purpose of this study was to gain insight into the participatory research process and the benefits participant researchers may have received from their participation. The potential sample selection bias and the lack of information about the size and characteristics of the population being studied limited the appropriate data analyses primarily to descriptive statistics and restricted the ability to generalize the findings from this study to other consumer/survivor researchers. Future studies that propose to make broader statements about consumer/survivor researchers would benefit from the inclusion of such individuals in the research in order to better define the population of interest and address the challenges of sample recruitment.

The five scales in the instrument were created by aggregating items with relevance to the construct of interest. While three of the five scales had acceptable Alpha coefficients (≥ .70), two of the five scales (interpersonal outcomes and endorsement of participatory methods of research) had coefficients in the low range, (.52 and .62, respectively), indicating that the internal reliability of those scales was questionable. The reliability of the interpersonal outcome scale would likely have been improved by increasing the number of scale items relevant to the construct. The endorsement scale which measured respondents' views of participatory methods would have been improved by testing the scale with a broader pilot sample of independent raters, and especially with consumer/survivors whose views might not have been reflected in the literature from which the items were derived. Feedback from these additional sources would likely enhance scale construction and improve the scales' internal reliability.

Conclusions, Implications, and Recommendations

One of the goals of this study was to better understand the phenomenon of participatory research as it is used in mental health and its impact on the individuals who participate. There is limited information available in the current literature about the characteristics of mental health consumer/survivor researchers, the environments in which mental health participatory research is conducted, and the features of consumer/survivors' participation. Also, only a few anecdotal accounts related to specific research projects about the

experiences and outcomes that mental health participants have achieved as a result of their involvement in research were found in the literature. This study was designed to elicit information from a broader sample of mental health consumer/survivor researchers regarding their overall research experiences and the effects of their experiences on their lives. The aim was to help fill the gaps in what is known about participatory research in mental health.

A secondary goal of this study was to determine if the views of consumer/survivor researchers regarding the benefits of their participation in mental health research supported the position of research professionals, as well as other consumer researchers, that participation in research is an empowering experience.

The findings from this study have provided some insights about who the consumer researchers are in mental health research as well as information about the environments in which participatory models have been used. The findings also have helped to identify the factors associated with consumer/survivor participation that are consistent with the elements of empowerment, the oft-cited raison d' 'etre for participatory research methods.

The findings from this study also lead to an important conclusion. Participation in research is positively related to positive individual change, especially if the interpersonal relationships among the researchers are respectful and affirming. Participants in this study reported that they experienced positive changes in the personal, social, and political aspects of their lives as a result of

their involvement in mental health research, a finding that was consistent with the views of other participant researchers who have reported that their involvement in research was positive and that they had benefited from the experience.

Implications for Social Work Practice

The theoretical framework for this study was empowerment. One of the fundamental goals of social work practice has been the empowerment of individuals who have been marginalized or oppressed (Robbins et al. 1998). Therefore, the use of research methods that have the potential for facilitating the empowerment of participants is highly consistent with the values and principles of the social work profession. However, there is more to participatory research methods than just engaging partners. The findings of this study indicate that the quality of the relationships among the professional and participant researchers appear to make a difference in terms of the benefits that are achieved. Perhaps it is less about who controls the research process as it is about what constitutes authentic inclusion from the participant researcher's perspective. If that is true, the more that is learned about what constitutes authentic participation, the more likely the hoped-for benefits of improving the science as well as the empowerment of individuals will be achieved.

As consumer researchers grow in numbers and expertise, the research community will be pressed to accept their contributions. There is evidence that funding agencies are already recognizing the importance of involving consumers/survivors in the establishment of their research agendas and

requiring that their grantees involve participant researchers (Green, 2003; Seifer, Kauper-Brown, and Robbins, 2004). Similarly, consumers/survivors are likely to exert pressure for their inclusion from the very beginning of the process. Consumer/survivor researchers have also begun to conduct their own research. There are also opportunities for new partnerships, but this may require social workers trained in traditional paradigms of research to be "re-educated" in participatory methods and the dynamics of shared power and control.

Recommendations

Notwithstanding its limitations, this study should be viewed as one step toward better understanding of the necessary and sufficient conditions for participatory research to be successful for all involved. There are, however, several recommendations for future research in this area.

Future Research.

First, as has been suggested throughout the discussion of the methodological limitations of this study, future studies about participatory research in mental health would benefit from the inclusion of consumer/survivor researchers as real partners in the process. While this study engaged mental health consumer/survivor researchers as consultants to the study, they were not involved as full partners, partly because of their own priorities and time constraints, but also because of the limited role they were asked to fulfill, i.e., to serve as consultants to the process, a role considered in this study to be at the low end of the participatory continuum. Also, the constraints of conducting

research associated with a dissertation made shared ownership of the process less tenable. In addition, the fact that the research was unfunded meant that the consultants were not paid for their participation, an issue with which the investigator struggled. It resulted in reluctance on the part of the investigator to impose on their time and to set deadlines for materials to be reviewed. Consequently, based upon several comments made by the respondents who corresponded directly with the investigator, it was clear that the investigator's own biases and assumptions had shaped the research. Observations made by the consultants after reviewing the qualitative data provided by respondents made it obvious that many of the issues that respondents had raised likely could have been addressed earlier had there been more collaboration with the consultants. There was little question that this study would have been improved if the consumer/survivor perspective had been more integrated into the process. The contributions that they made to the research provide more than adequate rationale for suggesting that future studies related to mental health research be undertaken as a partnership that involves consumer/survivors in meaningful ways that include remuneration for their participation.

Second, such constructs as participation, empowerment, research and mental illness are extremely complex. It is naïve to believe that their meaning can be captured in a series of close-ended questions on a survey. A necessary complement to this more structured, quantitative approach is a more qualitative look at the participatory research experience. Engaging consumer/survivor

researchers in conversations about their experiences in participatory research would provide the rich detail that is not possible through a written survey. It would provide the opportunity for participant researchers to give meaning to their words in a way that is not possible otherwise. Future efforts will still face the challenge, however, of identifying, locating, and recruiting individuals who typically have been invisible in the process of research.

A third recommendation is to further investigate the differences between what is typically thought of as citizen participation and the participation of individuals with disabilities. This study did not attempt to compare the experiences of people with mental illnesses to those participant researchers without such disorders or with individuals who have physical disabilities. Whether or not the research experiences or outcomes for people with mental illnesses are different from people with other disabilities or without such challenges is an important question yet to be investigated. Undoubtedly, there may be circumstances that are unique to individuals who have either physical or mental disabilities that need consideration, but additional research is needed to better understand what those circumstances may be and their implications for the use of participatory methods.

Social Work Practice.

According to the Substance Abuse and Mental Health Services Administration (SAMHSA) (1999), social workers are now major providers of mental health services in the United States. As social workers are extend their

roles from providers of mental health services to mental health researchers, they can bring social work values to the research endeavor. Social work research is fertile ground for participatory models, given the profession's commitment to the principles of social justice and empowerment. However, to the extent that the academic preparation of social workers involves only traditional paradigms of research, they will be in no better position to foster true participatory models of research than any other traditionally prepared researcher. Consequently, social work education at all levels, but particularly doctoral education, should expose students to these different research approaches and prepare them to engage in authentic participatory research models.

Social workers enjoy a certain professional status because of their training and experience. They have power that derives from their status and the auspice under which they operate. The sharing of power is difficult, especially for a profession steeped in the traditions of caretaking, i.e., doing and advocating *for* others who could not speak or do for themselves. Nonetheless, participatory methods of research require a shift from traditional thinking of doing for others, to doing *with* others; it involves the sharing of power. Consequently, social workers who engage in participatory methods of research will need to recognize and address the inherent power differential that exists between professional and participant. They will need to be prepared to share control of the research process with participants who may not always agree with their views or who have different expectations of the research.

While social workers may have come to appreciate the importance of the involvement of individuals in their treatment and the value of partnership in the therapeutic relationship, they may have had less experience with inclusion in other practice venues, such as research. Yet social workers are in a position to influence change in the way research is carried out if they are willing to advocate for the need to include others in the research process when they have the opportunity. They can promote the use of participatory models among their research colleagues, and as educators they can expose future researchers to the principles and practice of participatory research.

Finally, social workers can model the change in traditional research paradigms through their own research activities. Through the inclusion of others and the collaborative process, social workers can demonstrate the values of participatory research models and the potential benefits for all who participate. From their research experience, they can contribute what they have learned to the knowledge base about participatory methods of research, an area about which much remains to be learned. It will take a commitment on the part of social workers, however, to engage in what can be a difficult process that often takes more time, effort, and resources than traditional methods, but one which shows promise for improving the science while empowering participants.

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APPENDICES

APPENDIX A

STUDY CONSULTANT RECRUITMENT LETTER

Dear

As you know, I am a doctoral candidate in the school of social work at Memorial University at St. John's, Newfoundland. For my doctoral dissertation I have proposed a project that hopefully will improve our understanding of participatory research models and how they affect the individuals who participate.

Working at the Institute, I am familiar with how participatory models of research help to improve the conceptualization, design and implementation of the research itself. However, I believe we know less about how these models affect the people who have been included in the research process. We have not asked individuals, in any systematic way, about how they have interpreted their research experiences and their associated outcomes. The survey I am conducting is attempting to collect such information in order to answer the following questions, with the goal being to improve our research practices for all who participate:

- What impact has their research experience had on their personal, interpersonal or political life?
- Was the nature of their experiences generally positive or negative and what factors contributed to their characterization of their experience?
- What are the views of people regarding the utility, desirability, and feasibility of participatory research models?

Because of your experience in mental health research, I would like to invite you to participate with me in this endeavor. Your assistance in serving as a consultant to this project would be greatly appreciated and will undoubtedly provide unique insights that will improve the process and outcomes of this research.

There are two levels of participation that I am requesting. First, I would like your help in the design of the research project, to assist in the development of the instrument that will be used in the mail survey, to help recruit potential survey respondents, and to assist in the interpretation of the data received. Second, I would appreciate your capturing your thoughts about participating in this particular research project by keeping an informal journal (which I will provide to you) of this experience. I am keeping one as well. During the course of this project we can share with each other as much, or as little, of our journals that we

APPENDIX E

SOURCES OF STUDY DOMAINS

Table E.

Source of Study Domains

Source	Survey Questions
Leaders of Self Help mvmnt	IV-15, IV-16, III-2
Leaders of Self Help mvmnt	III-16, III-17, III-18, III-19, IV-16
Leaders of Self Help mvmnt	
Leaders of Self Help mvmnt	III-9, III-10, III-11, III-23, IV-3, IV-19, IV-20
Leaders of Self Help mvmnt	IV-5, IV-6, IV-12, IV-15
Leaders of Self Help mvmnt	
Leaders of Self Help mvmnt	
Leaders of Self Help mvmnt	III-1, III-2, III-3, III-5, III-6, III-7, III-8, III-13, III-14, III-15, III-22, III-25
Leaders of Self Help mvmnt	
Leaders of Self Help mvmnt	IV-5, IV-6
Leaders of Self Help mvmnt	III-21, IV-4,
Leaders of Self Help mvmnt	IV-10, IV-11,

Source	Survey Questions
Leaders of Self Help mvmnt	III-6, III-9, III-5
Leaders of Self Help mvmnt	IV-19
Leaders of Self Help mvmnt	IV-5, IV-6, IV-18, V-12, IV-3
Howie the Harp	
Howie the Harp	IV-20, IV-16
Howie the Harp	IV-16,
Howie the Harp	IV-16
Howie the Harp	
Howie the Harp	III-2
Howie the Harp	IV-15
Howie the Harp	IV-19
Rappaport (Psychology)	IV-19,
Rappaport (Psychology)	IV-19, IV-6, IV-5
Geller, Psychology	IV-7
Geller, Psychology	III-21, III-22, III-25,
Geller, Psychology	III-1, III-2, III-3, III-7, 111-11
Geller, Psychology	
Geller, Psychology	III-1, III-2, III-3, IV-11, IV-12
Geller, Psychology	IV-6, IV-15
Geller, Psychology	IV-16,
Zippay, Social Work	
Zippay, Social Work	IV-4,
Zippay, Social Work	IV-16
Nelson, et al, Psychology	IV-15, IV-16
Nelson, et al, Psychology	IV-16
Nelson, et al, Psychology	IV-10, IV-13
Nelson, et al, Psychology	III-16, III-17, III-18, III-19, IV-8, IV-16
Pinderhuges, Social Work	IV-16

Source	Survey Questions
Pinderhuges, Social Work	
Pinderhuges, Social Work	IV-5, IV-6, IV-15
Salzer, Psych/social work	IV-14
Salzer, Psych/social work	
Salzer, Psych/social work	
Salzer, Psych/social work	
Salzer, Psych/social work	IV-15, IV-6,
Salzer, Psych/social work	III-1, III-2, III-3, III-5, III-6, III-7, III-11, III-13, III-14, III-15, III-17, III-18, III-19, III-22, III-24, III-25
Staples, Social Work	IV-5
Staples, Social Work	IV-4, IV-16, IV-19,
Staples, Social Work	IV-15, IV-19
Staples, Social Work	IV-3, IV-18
Beresford, social work	
Beresford, social work	IV-16, III-5
Beresford, social work	
Beresford, social work	III-22,
Beresford, social work	IV-20

APPENDIX F

QUESTIONNAIRE FOR INSTRUMENT PILOT TESTING

Thank you for agreeing to participate in the pilot test of this survey. The survey will be distributed to people who have a personal experience with a mental illness and who participated in mental health related research in a role other than as a subject/respondent. The survey will be distributed via mail or e-mail with options to complete it online or in hard copy. (The online version is identical to this one, but is not yet available.) The survey is intended to assess the experiences of the individuals who have been involved in participatory models of mental health research.

I would greatly appreciate your feedback regarding the following areas after you have completed the survey. You may use the back of this sheet for your convenience. Thank you again for your help.

- Length of survey
- Format
- Clarity of directions
- Clarity of questions and statements
- Reading level of the survey
- Questions/statements that might be offensive
- Incentive provided (charitable donation)
- Other suggestions/recommendations

Name (Optional) _____Date_____

Length of time to complete survey_____

Length of Survey

Format

Clarity of Directions

Clarity of Questions/Statements

Reading Level

Offensive Language/Questions/Statements

Incentive (contribution to a charity)

Other Suggestions/Recommendation

Participation in Research: A path to personal, interpersonal, and political change for participant researchers?

The following questions are designed to obtain information about the research experiences of individuals who have, or have had, a mental illness (broadly defined) and who have participated in mental health in research activities. For purposes of this survey, **participation in research means that a person has been involved in formal research activities in some capacity other than as a respondent or subject of the research.** For example, a person might have collected data, or helped to analyze the data once it was collected. The size or scope of the research projects may vary, as could the role of the individual who participates with other research professionals in the project.

It should take approximately 20 minutes to complete. Your answers are confidential. This study has the approval of the Interdisciplinary Committee on Ethics in Human Research at Memorial University, St. John's Newfoundland. By completing this survey, you will help to create a better understanding of important issues related to participatory models of research.

I. Involvement in Research

1.) As a person who has, or has had, a mental illness, have you ever been involved in a mental health research project in some way other than as a respondent/subject?

- ☐ Yes
- ☐ No

If the answer to this question is "no" you need not proceed further. Please return the survey to the address noted on the last page. Thank you for your time.

2.) Are you currently involved in mental health research in some way other than as a research respondent/subject?

- ☐ Yes
- ☐ No

3.) Are you employed primarily as a mental health researcher?

- ☐ Yes
- ☐ No, I am regularly employed and I participate in mental health research, but mental health research is not my primary job
- ☐ I am not employed, but volunteer my time on research projects
- ☐ I am not regularly employed, but do get paid for my time and expenses for the work I do on research projects
- ☐ I choose not to answer this question

4.) How long have you been involved in research activities?

- ☐ 10 yrs. or more
- ☐ 5-9 yrs.
- ☐ 2-4 years
- ☐ One year or less
- ☐ I choose not to answer this question

5.) How many research projects would you estimate that you have participated in the last 3 years?

- ☐ 10 or more
- ☐ 5-9
- ☐ 2-4
- ☐ Only one
- ☐ I choose not to answer this question

6.) **What formal credentials do you have that helped prepare you to do research? (Please check all that apply)**

- ☐ Bachelor's Degree
- ☐ Master's Degree
- ☐ Doctoral Degree
- ☐ Other Specialized Training (Please specify)_____
- ☐ I have no formal credentials that prepared me to do research
- ☐ I choose not to answer this question

7.) **What life experiences have helped prepare you for your involvement in mental health research?**

_____
_____
_____

- ☐ I choose not to answer this question

8.) **What have been your PRIMARY roles in participating in research projects? (Please check all that apply)**

- ☐ Serving as the director or co-director of the project
- ☐ Designing research studies
- ☐ Collecting data
- ☐ Entering data on a computer
- ☐ Analyzing data
- ☐ Writing up research results
- ☐ Presenting research results at conferences/workshops/meetings
- ☐ Serving as an advisor
- ☐ Other (Please specify) _____
- ☐ I choose not to answer this question

II. The Research Environment

9.) **When you have participated in research projects did other members of the research team/project know that you have, or have had, a mental illness? (Please check only one)**

- ☐ Yes, in all instances
- ☐ Yes, some of the time
- ☐ No, I don't believe they knew
- ☐ I don't know
- ☐ I choose not to answer this question

10.) **In your research activities, how often do you think there were other people with mental illnesses also participating? (Please check only one)**

- ☐ In all instances
- ☐ Some of the time
- ☐ Rarely
- ☐ Never, as far as I know I am the only person among the researchers that I work with that has, or has had, a mental illness
- ☐ I don't know
- ☐ I choose not to answer this question

11.) In what type of agency have MOST of the research projects that you were involved with been conducted?
(Please check only one)

- ☐ Government agency
- ☐ University
- ☐ Private research organization
- ☐ Service providing organization
- ☐ I don't know
- ☐ I choose not to answer this question

12.) What are the PRIMARY sources of funding for the research in which you participated?
(Please check all that apply)

- ☐ Government agencies
- ☐ Foundations
- ☐ Private sources
- ☐ The research has not been funded by an outside source
- ☐ I don't know
- ☐ I choose not to answer this question

13.) Were there requirements to involve people with mental illnesses in the research activities in which you participated?
(Please check only one)

- ☐ Yes, in all cases
- ☐ Yes, in some cases
- ☐ No
- ☐ No, but involving people with mental illnesses was customary
- ☐ I don't know
- ☐ I choose not to answer this question

II. The Research Experience

14.) Thinking about your research experiences overall, please indicate the degree to which the following statements accurately reflect your experiences as a participant in research by placing an "X" in the box that best reflects your response.

(Please mark only one answer for each statement)

When I have been involved in research activities....	Always 1	Most of The Time 2	Some of the time 3	Rarely 4	Never 5
My views and recommendations were valued and acted upon.					
It was "safe" to express my opinions.					
Symptoms of my mental illness often prevented me from being a full participant.					
It was acceptable for me to seek emotional support from the other researchers when I needed it.					
If I needed special accommodations (for example, flexible hours), they were provided for me without any negative consequences.					
If I needed help with understanding research language and methods, other researchers willingly explained them to me.					

When I have been involved in research activities....	Always 1	Most of The Time 2	Some of the time 3	Rarely 4	Never 5
I received good feedback from the other researchers regarding my contributions.					
I was asked to participate in all phases of the research, including determining what research questions would be addressed.					
I did not feel like part of the research team because I was included in only some of the research activities.					
I did not feel I could really trust the other professionals with whom I worked.					
I felt welcome to participate in the research activities, but did not feel I would be invited to socialize with the other researchers.					
The professional researchers were unwilling to share their power.					
I had the same access to office space, equipment, and materials that other professional researchers had.					
My expenses (for example, childcare or transportation) were adequately covered.					
I had enough time and assistance to become adequately prepared to be a full participant.					
I was encouraged by other researchers to assume more responsibility.					
I was paid fairly for the work that I did.					
Other researchers treated me with respect.					
I had many opportunities to share my concerns, questions and perspectives with other researchers.					
I had an equal role in decision-making.					

IV. The Effects Of Research Participation

15.) Thinking about your overall experiences in research and the effect those experiences have had on your life, please indicate your level of agreement with the following statements by placing an "X" in the box that best reflects your views.

(Please mark only one answer for each statement)

As a result of my participation in research...	Strongly Agree 1	Agree 2	Disagree 3	Strongly Disagree 4
I have been able to make positive changes in the way I live.				
I have more confidence in myself.				
I learned new job skills.				
I am a better advocate for myself.				
I am more willing to advocate for other people with mental illnesses.				

As a result of my participation in research...	Strongly Agree 1	Agree 2	Disagree 3	Strongly Disagree 4
My friends that also have mental illnesses do not associate with me anymore.				
I lost benefits (such as food stamps, Social Security income, health benefits) that were important to me.				
I have been offered other types of work.				
People seem to respect my opinions more.				
I have been asked to participate in research projects so often that it has become a problem for me.				
I have made new friends among the researchers I work with.				
I have been able to affect decisions about mental health policies or practices.				
Everyone but me benefited from my contributions to the research.				
My health has been adversely affected.				
I understand my own mental illness better.				
I have received promotions/pay increases at work.				
I have become better known as a researcher.				
I have been able to positively affect other people's attitudes about working with people who have a mental illness.				

V. Your Opinions of Participatory Methods of Research

16.) Please indicate your level of agreement with the following statements by placing an "X" in the box that best reflects your views.

(Please mark only one answer for each statement)

I believe that...	Strongly Agree 1	Agree 2	Disagree 3	Strongly Disagree 4
Involving people with mental illnesses in mental health research improves the research process and outcomes.				
Based upon my experiences, I would recommend that other people with mental illnesses participate in mental health research.				
Research benefits the research professionals involved, but not the non-professional participants.				
Including people with mental illnesses in research projects requires extra time, effort, and expense for the project.				
Participating in research is a good way for people to gain a better understanding of their own mental illness.				
Funding agencies should require researchers to involve people with mental illnesses in the mental health research process.				

I believe that...	Strongly Agree 1	Agree 2	Disagree 3	Strongly Disagree 4
Professional researchers are not likely to share their power with non-professional participants involved in the research.				
Participating in research is a good way for people who have a mental illness to influence mental health policies and practices.				
It is not always practical or desirable to include people with mental illnesses in mental health research.				
People with mental illnesses should do their own mental health research, not just participate in mental health research done by other professional researchers.				

VI. Personal Characteristics

This final section asks you a few questions about yourself.

17.) Age
- ☐ 21-30
- ☐ 31-40
- ☐ 41-55
- ☐ 55+
- ☐ I choose not to answer this question

18.) Gender
- ☐ Male
- ☐ Female
- ☐ I choose not to answer this question

19.) Race
- ☐ White
- ☐ Black/African American
- ☐ Asian
- ☐ Pacific Islander
- ☐ Native American
- ☐ Other (Please specify): _____
- ☐ I choose not to answer this question

20.) Are you Hispanic?
- ☐ Yes
- ☐ No
- ☐ I choose not to answer this question

21.) Annual Income
- ☐ Under $5,000
- ☐ $5,000 - $19,999
- ☐ $20,000 - $39,999
- ☐ $40,000 - $59,999
- ☐ $60,000 - $79,999
- ☐ $80,000 -
- ☐ I choose not to answer this question

APPENDIX H

SURVEY MONKEY SECURITY POLICY

Survey Monkey policy states that we will not use your data for our own purposes.
The data you collect is kept private and confidential.
In regards to the security of our infrastructure, here is an overview of our setup.

We do offer SSL encryption for the survey link and survey pages during transmission.
The cost is an additional $9.95 per month.

The servers are kept at SunGard.
http://www.sungard.com

Physical

- Servers kept in locked cage
- Entry requires a passcard and biometric recognition
- Digital surveillance equipment
- Controls for temperature, humidity and smoke/fire detection
- Staffed 24/7

Network

- Multiple independent connections to Tier 1 Internet access providers
- Fully redundant OC-48 SONET Rings
- Uptime monitored every 5 minutes, with escalation to SurveyMonkey staff
- Firewall restricts access to all ports except 80 (http) and 443 (https)
- QualysGuard network security audits performed quarterly

Hardware

- Servers have redundant internal power supplies
- Data is on RAID 10, operating system on RAID 1
- Servers are mirrored and can failover in less than one hour

Software

- Code in ASP, running on SQL Server 2000 and Windows 2000 Server
- Latest patches applied to all operating system and application files

- SSL encryption of all billing data
- Data backed up every hour internally
- Data backed up every night to centralized backup system, with offsite backups in event of catastrophe

APPENDIX I

APPLICATION TO MEMORIAL UNIVERSITY INTERDISCIPLINARY COMMITTEE ON ETHICS IN HUMAN SUBJECTS RESEARCH

Application for Ethics Review

Brief Statement

Mental Health Research: A Path to Personal, Interpersonal, and Political Change for Consumer Researchers?

The purpose of this dissertation study is to contribute to the understanding of the experiences of mental health consumers who have participated as researchers in the research process. Most often, consumers have been involved as subjects of research rather than as partners. They have had little control over the process and have rarely benefited directly from the research that has been conducted about them. However, participatory research models have emerged as consumers have asserted their expectations that they be involved in research that is about them and as professionals have come to appreciate the contributions of people who have personal experience with the issues with which the research is concerned.

While the professional literature describes the benefits that accrue to consumers as a result of participating in research, there is scant

evidence of the consumers' view of the benefits and/or harms they may have experienced. There is even less evidence of any attempt to survey consumers about their experiences as researchers on a scale broader than a specific project or study. In this study, consumer researchers across the United States will be surveyed by mail using a snowball sampling approach. The survey instrument to be used was initially developed through the review of relevant literature and will be subsequently refined with the help of consumer researchers who will be recruited to serve as consultants to this study. The survey is designed to address the following research questions:

- What impact has the research experience of mental health consumers had on their personal, interpersonal, and political lives?
- Was the nature of the consumer researchers' experience generally positive or negative and what factors contributed to their perspectives about their experiences?
- What are the views of consumer researchers about the feasibility and usefulness of participatory research models?

The importance of the study results lies not in the generalizability of the data, but rather in having a broader understanding of the implications and consequences for consumers who become involved as researchers so that better

participatory research practices can be developed at the same time better science may be achieved.

Nature and Involvement of Human Subjects

The potential respondents to this survey that will be initially identified will include those mental health consumer researchers that are known to this investigator, either directly or by reputation (e.g., who have been identified through the literature, their participation or presentations in conferences). The respondents are likely to be currently employed as mental health researchers and living in the community. While they may have a mental illness, it is also very likely that they are successfully managing their mental health symptoms. The initial wave of potential respondents will receive additional copies of the letters of invitation and explanation as well as the survey and will be asked to distribute them to additional consumer researchers with whom they may be familiar and have contact. The second wave of respondents will also be asked to distribute a letter of invitation to individuals that they believe might meet the criteria for inclusion in the study. Individuals will be cautioned against suggesting individuals who may not wish to have the fact that they have a mental illness made known. Through this snowball sampling approach it is anticipated that a sample of at least 200 mental health consumer researchers will be identified.

Individuals will be provided a letter that fully explains the study, its purposes, and the fact that participation is voluntary and that if they decide to

participate, they may choose to withdraw at any time from the study without consequence. They will be advised that if they choose not to participate that they may simply discard the materials. Individuals in the initial mailing who fail to return the survey will receive three subsequent mailings (a postcard, a second survey and a follow-up letter) encouraging their participation.

In addition to the survey respondents, a small cadre (no more than 5) of mental health consumer researchers who are known professionally to this investigator will be invited to consult on this study by way of a letter that explains the purpose of the study, what they are being asked to do, how the data will be used, as well as the safeguards in place to protect their confidentiality. They will be advised that their participation is voluntary and that they may withdraw from participation at any time without consequence. They will be involved in the design of the study, the development of the survey instrument and in data analysis. They will be asked to draw upon their own experiences as consumer researchers as they help to inform the design and execution of this study. They will also be asked to keep a journal of their experiences as consultants to this project. (This investigator will also maintain a journal.) During the course of the study, there will be opportunity for the consultants and this investigator to share journal entries to the extent it is comfortable for everyone. They will be asked to provide their consent to include their perspectives, along with those of this investigator, as part of the data analysis and final report as well as in any publications in scholarly journals.

Harms and Benefits

There are minimal anticipated risks to the respondents and consultants in this study. Individuals will have the opportunity to refuse to participate in the study by failing to return the questionnaire or by requesting to be dropped from the study at any time. While the nature of the survey questions may be considered to be personal by some respondents, they have the option of refusing to answer any question that makes them uncomfortable. Individuals will be advised in the introductory letter that if they should experience any difficulty at any time during the completion of the survey, that they should contact their mental health professional. They will also be advised in the introductory letter that if they should have ethical concerns about the conduct of the study they may contact the chair of the Interdisciplinary Committee on Ethics in Human Research. The proposed study has no adverse bearing on the consultants' or respondents' rights and/or welfare.

Neither the respondents nor the consultants will be paid for their participation nor will they benefit directly. Survey respondents will receive a small token of appreciation (such as a coupon for free coffee or tea) for taking time to respond to the survey. At the end of the study, the consultants will be offered a small token of appreciation, such as a gift certificate for a restaurant, for their participation.

There are no other anticipated benefits to the respondents in this research. However, it is hoped that the findings from the study will provide

valuable information about creating better strategies for inclusion of mental health consumers in mental health research.

Scholarly Review

This research study is a requirement of the Ph.D. program of the School of Social Work at Memorial University of Newfoundland. As indicated by the signature of the Supervisor of the dissertation committee, scholarly review and approval has been conducted by the School of Social Work.

Free and Informed Consent

Written informed consent will not be obtained from survey respondents. However, each potential respondent will receive an introductory letter that explains the study and its purposes, an estimation of the time it will take for them to complete the survey, and the procedures for ensuring the confidentiality of their responses. Also, in the explanatory letter individuals will be notified that they have a right to withdraw from the study at any time by notifying the investigator of their wish to withdraw. They will be advised that if they choose not to participate that they may simply discard the materials they received. It will be assumed that respondents who return their surveys are providing informed consent by virtue of their participation.

Written informed consent will be obtained from the research consultants in order to include the data generated by their journaling activities in the final report and any subsequent publications in scholarly journals.

Privacy and Confidentiality

Respondent identities will be protected through the use of coded survey forms and all data will be aggregated without personal identifiers when analyzed and presented. Only this investigator will have access to the code that identifies individuals and that information will be kept secured in a locked filing cabinet. All raw data will remain in a confidential and secure environment. Data that has been entered by this investigator into a computer will be kept on in password-protected computer file. A back up disc with a password-protected file will be kept in a locked cabinet. Consumer consultants will have access to de-identified data only. The identities of the consumer researchers will be known. However, any data (such as notes or journal entries) that are generated through their involvement in this study will be maintained in a locked filing cabinet and will be only available to this investigator.

When the study and dissertation have been completed, all study data will be destroyed.

Conflict of Interest

The proposed research does not involve any actual, perceived or potential conflict of interest for this investigator.

Inclusiveness

Participation in this study is open to adults (aged 21 and older) who have personally experienced a mental illness, broadly defined, as an adult. The fact that they may not have disclosed that they have a mental illness does not

preclude them from participation in this study. Their experience in research must have been as a research colleague versus as a subject of research; they must have had at least one experience of participation in mental health research as a research colleague, although their participant roles may have varied. There are no exclusions based upon gender, race, ethnicity, or sexual orientation.

Aboriginal Peoples

This research study does not involve Aboriginal peoples as human subjects.

APPENDIX J

LETTER TO THE UNIVERSITY OF SOUTH FLORIDA ETHICS REVIEW BOARD

Memorandum

November 16, 2003

To: Paul Stiles, Chair, Institutional Review Board

From: Pat Robinson, M.S.W.

Re: Ethics Review for Dissertation Research

As you may be aware, I am a doctoral candidate in the School of Social Work at Memorial University in St. John's, Newfoundland. I have submitted my research proposal and all related documents for ethics review and have received approval to proceed with my research from the Interdisciplinary Committee on Ethics in Human Research at Memorial.

Because I am conducting this research under the auspices of the social work doctoral program at Memorial rather than the University of South Florida, I was told upon inquiring earlier, that I would need only to submit copies of the materials that I had submitted to Memorial, along with their letter of approval as informational items to the USF Ethics Review Committee. The relevant materials are attached. Please let me know if I any additional information is required. Thank you.

Pat Robinson, M.S.W.

Attachments

Cc: Ross Klein, Ph.D., School of Social Work, Memorial University
Roger Boothroyd, Ph.D., Florida Mental Health Institute, University of South Florida
Mike Ungar, Ph.D., School of Social Work, Dalhousie University

APPENDIX M

LETTER OF RESPONSE TO MEMORIAL UNIVERSITY INTERDISCIPLINARY COMMITTEE ON ETHICS IN HUMAN SUBJECTS RESEARCH

Mrs. Eleanor Butler
Coordinator, Interdisciplinary Committee on Ethics
In Human Research
Office of Research
Memorial University
St. John's, Newfoundland CA A1B 3X5

Re: ICEHR No. 2002/03-101-SW

Dear Ms. Butler:

This letter is in response to the ICEHR's review of my recent proposal for my doctoral research project entitled: "Mental Health Research: A Path to Personal, Interpersonal, and Political Change for Consumer Researchers." I have amended the various documents in accordance with the changes indicated in the September 8, 2003 letter from Ms. Parsons. Indicated below are the specific amendments that I have made.

1. With respect to the need for more of an arms-length approach, I have removed from the survey form and letters of recruitment any request for the names of individuals that I might contact directly to issue an invitation to participate in the study. I will rely on the first and second waves of individuals to provide the letters of invitation and copies of the surveys to additional individuals. In the letters to respondents that request their assistance in providing the materials to additional potential respondents, they are cautioned not to provide them to anyone who may not want the fact that they have a mental illness known and to not reveal to me to whom they have distributed the letters of invitation. The letters of invitation to the second and third waves of potential respondents indicate that they are under no obligation to inform the individual from whom they received the letter and survey about their decision to participate.

   I have also removed the word "Important" from the documents in order to alleviate any perception of undue pressure to participate in the study.

2. I have indicated in the letter of invitation to the consultants that I am requesting their permission to use notes from our interactions, as well as any journal entries they care to share during the course of the project, as part of the data to be

included in the dissertation as well as any subsequent publications in scholarly journals. I have also outlined the procedures by which their confidentiality will be protected. Enclosed you will also find the newly developed adult consent form that they will be asked to sign if they agree to participate as consultants in the study and to allow me to use any data they should make available to me.

3. I have indicated to both survey respondents and the consultants the estimated amount of time that will be required of each of them to participate in the project.

4. I have included in each letter of invitation language that indicates that they have the right to refuse to answer any particular question and that they may withdraw from the study at any time without consequence. I also added language indicating that at the end of the study and the completion of the dissertation, all data will be destroyed.

5. I have indicated to each prospective respondent that if they choose not to participate in the survey, they should discard the survey document and letters of invitation. They are encouraged to use the coupons provided as a token gesture of appreciation for their time and consideration.

6. Once approval to recruit the consultants is received, they will be asked to review the draft survey questions that I have constructed based upon a review of the literature. Changes that are recommended to the survey will be re-submitted for review and approval of the Committee on Ethics in Human Subject Research prior to their being mailed to potential respondents.

7. Recruitment letters, survey instruments and the consultant consent form all include the provision that the respondents or consultants have the right to contact the Committee on Ethics in Human Subject Research, if they so choose.

8. I have also enclosed an additional letter of invitation that would be distributed by the second level of responders to additional potential respondents. This letter was inadvertently left out of the previous submission. It requests the third level of potential respondents to contact me by phone or email if they would like to participate in the study, at which time a cover letter and survey will be sent to them for completion.

I hope I have adequately responded to each of the Committee's concerns. Please let me know if you need any additional information. I look forward to hearing from the Committee. Thank you.

Pat Robinson, M.S.W.
Doctoral Candidate