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The Development of a Self-Report Scale for the Assessment of Stigma and Discrimination as Experienced by Individuals with Schizophrenia

by

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ABSTRACT

Despite the many improvements in treatments used to alleviate the symptoms of schizophrenia, the social stigma of having a mental illness continues to jeopardize these advances. Many myths and misunderstandings about schizophrenia and its treatment persist, resulting in stigma and prejudice against those who have schizophrenia. Stigma creates a vicious cycle of alienation and discrimination that can lead to a reluctance to seek care.

A change in public attitudes is necessary to reduce the stigma associated with mental illness. Now many public and advocacy initiatives exist toward reducing this stigma. As there is no scale to measure the stigma actually felt by those who are mentally ill ("felt stigma"), it is not possible to evaluate the impact of these programs on the consumer. The goal of this study was to develop a self-report questionnaire designed to assess stigma and discrimination because of schizophrenia from the viewpoint of the consumer.

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Dedicated to those people with a mental illness and their families whose courage in the face of hardship has been a vital source of my inspiration and commitment to improving the quality of their lives.

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CHAPTER ONE: INTRODUCTION AND PURPOSE

1.1 Introduction to the Research Problem

Stigma is central to an individuals' and their families' experience of mental illness. The term *stigma* refers to a stable characteristic or attribute of an individual that is perceived as damaging to the individual's reputation (Goffman, 1963). A rich international literature has now documented the existence of stigmatizing attitudes among the general population. Recent empirical findings indicate that persons with severe mental illness such as schizophrenia are viewed negatively by the public (Brockington, Hall, Levings, & Murphy, 1993; Wolff, Pathare, Craig, & Leff, 1996b; Parra, 1985; Trute, Tefft, & Segall, 1989; Ng, Martin, & Romans, 1995; Raguram, Weiss, Channaasavanna, & Devins, 1996; Brand & Clairborn, 1976; Angermeyer & Matschinger, 1994). Interestingly, the negativity toward persons with severe mental illnesses is not limited to members of the community but can also be found among mental health professionals (Eker & Arkar, 1991; Lawrie et al., 1996; Lyons & Ziviani, 1995; O'Connor & Smith, 1987; Wahl, 1987; Williams, 1990).

Despite this large body of work, stigma has only been measured in terms of public expressions of intolerance and social distance. There has been little interest in documenting stigma from the perspective of the stigmatized. In studies of cultural relations, for example, there has been only one attempt to measure 'felt' stigma from the perspective of the stigmatized minority group members (Lee & Ray, 1996). In the field of mental health, there has been no attempt to measure stigma from the mental health

consumer's perspective. Indeed, no measure of 'experienced' or 'felt' psychiatric stigma currently exists. Yet, social stigma has been identified as the single most important factor undermining the quality of life of both the individuals with mental illness and their family members (Holley, 1998; Rosenfield, 1997). Stigma activates expectations of rejection and strategies for self-protection in people with mental illness (Sibicky & Dovidio, 1986; Link, 1987; Link et al., 1989). It creates a vicious cycle of alienation and discrimination, that can lead to social isolation (Leary, Johnstone, & Owens, 1991), inability to work (Farina, Gliha, Boudreau, & Sherman, 1971; Link, 1982; Link, 1987), homelessness (Bachrach, 1992), excessive institutionalization (Perese, 1997). Stigma can lead to low self-esteem and depression (Farina et al., 1971; Link, 1987; Wahl & Lefkowits, 1989), a reluctance to seek care (Ben-Noun, 1996), poor compliance to treatment plans (Lysaker, Bell, Milstein, Bryson, & Beam-Goulet, 1994), or death (Anderson, Connelly, Johnstone, & Owens, 1991).

Schizophrenia is a brain disorder characterized by delusions, hallucinations, and other disturbances in thinking and communication, and by deteriorating social functioning. As the age of onset is usually between 16 and 25 (Häfner, Hambrecht, & Loffler, 1998), and because teens with schizophrenia have a very high risk of attempted suicide, it is considered "Youth's Greatest Disabler" (Holt, 1996). Schizophrenia is found all over the world in all races, in all cultures and in all social-economic classes. It affects one in 100 people worldwide (Häfner & Heiden, 1997; Bland, Newman, & Orn, 1988) that is about 306,000 Canadians (Statistics Canada, 1998). The cost to Canadian society is in the billions of dollars annually. In 1989, the total direct (e.g., hospitalization) and indirect

costs (e.g., lost productivity and impact on family income) of schizophrenia in Canada was estimated to be $5.8 billion (Van den Berg, 1995). In 1990, schizophrenia was ranked ninth of all causes of disability worldwide based on the years lived with a disability (Murray & Lopez, 1996).

Schizophrenia is treatable with medication and rehabilitation programs. Appropriate treatment is essential to control symptoms, especially among those in whom the disease becomes chronic. However, many myths and misunderstandings about schizophrenia and its treatment persist. It is thought that these misunderstandings are largely responsible for the stigma and prejudice affecting those who have or have had schizophrenia, as well as their families. Because stigma results in a host of negative psychological and social effects despite the fact that psychiatric symptoms can be controlled (20%) or ameliorated (20-25%) in a substantial number of people (Warner, 1994). Consequently, fighting the stigma and discrimination associated with schizophrenia remains a key public mental health goal.

Professionals seem to agree that to reduce the stigma associated with mental illness, it is first necessary to change public attitudes, and many public education and advocacy initiatives now exist toward this end (Peterson, 1986; Penn et al., 1994; Sartorius, 1997). However, as there is no scale to measure felt stigma, it is currently not possible to evaluate the impact of these programs on the consumer; that is the extent to which they improve the circumstances of the mentally ill. In this era of improved accountability, it will become increasingly important to evaluate the outcomes of these public education initiatives more directly. Having a reliable and valid measure of stigma as

it is experienced by the mental health consumer, will be key to achieving this goal.

The need for a stigma scale to measure consumers' perspectives was identified within the context of the World Psychiatric Association's (WPA) *Global Program Against Stigma and Discrimination Because of Schizophrenia*. The investigator, supervisor, and two committee members are members of the Local Action Committee of the Pilot Test Site in Calgary, Alberta. The goal of the pilot program is to develop and evaluate appropriate public education materials that could be used globally, as the program expands to other countries.

1.2 Purpose of the Study

In response to this need, this study has two goals: (1) to develop a self-report questionnaire designed to assess stigma and discrimination because of schizophrenia, (2) to assess the content validity and procedural feasibility of this questionnaire among selected individuals diagnosed and receiving treatment for schizophrenia. This study is the first stage in a larger research process aimed at a full psychometric assessment of this questionnaire.

1.3 Study Objectives

1) Develop a self-report questionnaire to assess stigma and discrimination among patients diagnosed with and receiving treatment for schizophrenia initially based on themes identified from the published personal accounts of stigma and discrimination and descriptions written in qualitative studies about life

experiences of individuals with schizophrenia, then augmented with concepts identified in the literature on stigma.

2) Evaluate the comprehensiveness of the substance and content (content validity) of the questionnaire as judged by an expert panel of local and international experts.

3) Evaluate the clarity of the instructions and questions using fellow classmates of the Masters Program of the Department of Community Health Sciences.

4) Evaluate the content, appropriateness, feasibility, and ease of use of the questionnaire in a small and selected sample of 10-15 individuals with schizophrenia (pilot-test).

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This chapter will review the current literature on stigma because of mental illness. It will begin with an overview of stigma and an acquisition theory of stigma. Next, attitudes towards mental illness, and strategies to reduce stigma and discrimination will be examined. The chapter will conclude with a conceptual framework intended to (a) summarize existing literature and, (b) to form the basis for subsequent scale design.

2.2 Literature Review

2.2.1 Stigma: An Overview

2.2.1.1 The Origin of Stigma

The term *stigma* originated from the Greek culture and was used to refer to bodily signs designed to expose something unusual or bad about the moral status of the 'branded' to their people. The signs were a brand or scar burned or cut into the body (a mark) signifying that the bearer was a slave, a criminal, or a traitor; someone to be avoided (Goffman, 1963; Clausen, 1981). In later times, the term was used more to signify the disgrace itself, rather than the physical signs of it. Currently, a person with a stigma possesses an undesired deviation from the expected norm within their community that is deeply discrediting and reduces that individual from a whole and usual person to a tainted discounted one (Goffman, 1963; Jones et al., 1984).

Thus, stigma is socially and culturally defined and refers to an aspect of

relationships. It is seen as a "mark" that sets a person apart from others and links the marked person to undesirable characteristics (Jones et al., 1984). To be labeled as "stigmatized", normative deviations in physical attributes, character, or behaviour must be undesirable; being different in itself is not stigmatizing. "Normals" according to Goffman (1963) are classified as those in the community "who do not depart significantly from the particular expectations at issue" (p. 5).

2.2.1.2 Stigma as an Undesired Deviance

A deviance can lead others to judge individuals as illegitimate for participation in an interaction, if they are perceived as incompetent, unpredictable, inconsistent, or a threat to the interaction. Routine social interactions proceed when all involved consider themselves and each other to be legitimate participants. Legitimacy is a status that is claimed by an individual but must be conferred by others. The benefit of achieving legitimate status is to come under the protection of a number of implicit social norms. A person without legitimate status lies outside the boundaries of these social norms and is not entitled to their protection. Consequently, the person may find it exceedingly difficult, if not impossible, to realize the goals of any encounter (Elliott, Ziegler, Altman, & Scott, 1982).

Six dimensions can characterize social norms: (1) Norms may prescribe or proscribe conduct or merely indicate the type of behaviour, which is preferred or permitted. (2) The extent of agreement concerning such norms will vary within society. (3) There are likely to be varying degrees of commitment amongst those who accept a

particular norm. (4) Informal or formal sanctions may be applied to those who fail to conform to a particular social norm. (5) Norms differ in the type of adherence required (i.e., norms may require implicit or explicit support). (6) The elasticity of norms will vary. With some norms, adherence to a restricted range of conduct may be required whereas greater flexibility may be permitted with others (Merton & Nisbet, 1971).

The reactions to norm infractions are likely to vary to some degree. The public may respond to deviance in a number of ways. It can be indifferent, welcoming, (e.g., heralding deviance as a way for society to advance) punitive, or progressive (e.g., advocating certain measures as ostensibly designed for the deviant's 'own good'). Therefore, stigma will not necessarily be attached to all types of norm infractions. In general, stigma has tended to be associated with those inferior attributes that are commonly regarded as major norm infractions. It should also be noted that the rationale for a particular stigma might change over time (Cohen, 1971).

2.2.1.3 Types of Stigma

Erving Goffman (1963) distinguishes between three different types of stigma: (1) physical defects and deformities, (2) blemishes of character (including mental disorders and suicide attempts), and (3) tribal stigma related to race, nation and religion. Goffman also outlines two ways in which each type of stigma may be carried. The "discredited" describes an individual whose difference is evident. In contrast, the "discreditable", describes an individual whose difference is not immediately apparent. In general, those with physical or tribal stigmas will tend to be discredited rather than discreditable,

whereas, individuals with conduct stigmas are more likely to be discreditable than discredited.

2.2.1.4 Recognition and Reaction

Individuals may recognize they possess a stigma in two ways. First, they may recognize stigma through a process of self-recognition. As a result of socialization, most members of society gain an understanding of the various types of prevailing stigma. They, then, are in a position to compare their own conduct or appearance with existing stigma types. If they find that their appearance or conduct mirrors a particular stigma type, they may conclude that they possess a stigma. The second way in which individuals come to recognize that they possess a stigma is through the reactions of others. These reactions may be direct (e.g., a psychiatric patient being called crazy) or indirect (e.g., an individual hearing the negative attitudes attributed to people with a mental disorder). Many individuals come to recognize that they have a stigma by a combination of self-recognition and audience reaction (Goffman, 1963).

All individuals who carry stigmas are likely to experience feelings of stigma to some degree. For those with conduct or tribal stigmas, the adverse comments or actions of others may induce such feelings. For the physically stigmatized, feelings of stigma are more likely to be experienced as a result of the inhibited or over-sympathetic reactions of normals (Page, 1984). The stigmatized feel that others are not willing to make contact with them on equal ground. Shame becomes a central feature, as well as self-hate or self-derogation (Goffman, 1963).

Social situations are made uneasy by the reactions of both the stigmatized and the stigmatizer. The anticipation of such contacts can lead normals and the stigmatized to arrange life so as to avoid contact. Lacking the salutatory feedback of daily social interactions with others, the stigmatized self-isolates and can become suspicious, depressed, hostile, anxious and bewildered. Patients may avoid treatment and social contact to prevent rejection (Goffman, 1963).

2.2.1.5 Stigma Management

Goffman distinguishes between "passing" and "covering" as two main ways individuals can manage their spoiled identities. Passing involves deliberate concealment of the mark, while covering involves subtle strategies to keep the stigma from being overly intrusive in particular interactions. Passing is tempting when the stigma attached to the mark is great and the mark is easily concealed (as with the discreditable). It is expected that passing is often used by former mental patients, ex-convicts, and prostitutes. The decision to pass can be a deliberate pre-planned response to the likelihood of detection, or may emerge naturally. In cases of sensory deficiency and physical disability (as with the discredited) covering is attempted.

Goffman (1963) suggests that the degree of psychological strain involved in passing may be greater for those who believe in the therapeutic benefits of candour and disclosure. Difficulties and sources of strain are typical with concealment. Even when passers are successful, they might face prejudice against persons of their "own kind". The passer also faces the danger of discovery. Typically, when the duplicity is revealed those

from whom the mark was concealed will feel resentment. This is particularly true if the normal person considers himself close friends of the passer, since disclosure of such things is usually treated as an obligation of friendship.

One implication of planned disclosure is the importance of when to disclose the mark. The longer one waits to disclose, the more difficult it is to reveal the mark. Short-run concealment can be attributed to a lack of opportunity, or not wanting to appear to be looking for sympathy. When the passer is uncovered, however, the discredit of a deceitful lack of trust is added to the discredit of the revealed mark (Goffman, 1963). Jones and Gordon (1972) have shown that disclosure timing may depend on the degree to which the markable is seen as personally responsible for his mark.

Complete passing or "total disappearance" is very rare. Much more typical are the mixed cases, where the mark is concealed from some audiences and revealed to a select circle of friends and family. The danger in this is the potential confrontations between those who know and those who do not. If the markable generates a double biography, the segregation of identities may break down through a number of circumstances. Goffman (1963) provides this example: "Every ex-mental patient must face having formed in the hospital some acquaintances who may have to be greeted socially on the outside, leading a third person to ask, 'Who was that?'" (p. 67). Finally, in some instances where the markable may not be able to conceal the mark, they will work to convert its origin and significance.

The concept of self is challenged with the diagnosis of a mental illness and particularly with the experience of being hospitalized. Being committed to a psychiatric

hospital further challenges patients to make sense of why they are in the hospital and what that says about who they are. The struggle becomes one of defining a competent internal self-concept. The chronicity of a mental illness involves a continuous shifting of expectations and definitions of self. The following are different forms of conversion that have been identified to maintain a sense of competence (Lally, 1989):

1) choosing a less stigmatized label for one's illness (e.g., a woman diagnosed with schizophrenia linked her hallucinations and past history of bizarre behaviour to depression),
2) reducing the stigma of the label (i.e., by linking their condition with a great religious, political, or moral leader),
3) de-emphasizing incompetent aspects of the self by redefining one's behaviour and/or label (e.g., a patient who had done many bizarre things but never heard voices may say that crazy people speak to people who are invisible, thus defining the potentially stigmatizing condition to exclude their own actions),
4) emphasizing competent aspects of self (i.e., interjecting comments about past accomplishments or those of relatives when unrelated to the current conversation), and
5) separating the two aspects of self (e.g., a man stating that he is not in control when "it" comes over him - preserving one's self separate from his condition).

2.2.1.6 Prejudice, Discrimination, and Stereotype

Normals believe the person with stigma is not quite human and, on this

assumption, exercise a variety of discriminatory practices through which the life chances of stigmatized individuals are reduced (Goffman, 1963). The process just described involves three terms that have become somewhat blurred in their use in everyday speech: prejudice, discrimination, and stereotype. *Prejudice* refers to a special type of attitude (generally, a negative one) toward the members of some social group, based solely on their membership in that group. Prejudice may also involve beliefs and expectations about members of these groups - specifically, *stereotypes* suggest that all members of these groups demonstrate certain characteristics and behave in certain ways. In contrast, *discrimination* refers to negative actions taken towards those individuals (Baron, Byrne, & Watson, 1998).

2.2.2 Labeling Theory

Over the past three decades, research on the stigma of mental illness has been fuelled by interest in the labeling theory. The central position of the labeling theory is that social groups create deviance through making rules whose infractions constitutes deviance. Labeling theory proponents and the theory's critics have different views of stigma and thus differ on the consequences of labeling for people with mental illness. Proponents of the theory argued that the consequences of being labeled a "mental patient" are malevolent, while critics contended that the patient role (hospitalization and treatment) is in the long run beneficial or benign (Weinstein, 1983).

To proponents of the labeling theory the label rather than the behaviour per se, shapes the fate of mentally ill persons, by creating chronic mental illness or by

compromising the life chances of those so labeled (Link, 1982; Link, 1987; Link, Cullen, Frank, & Wozniak, 1987; Link et al., 1989; Scheff, 1974; Scheff, 1984). In contrast, critics of labeling theory view mental illness as a form of individual pathology. The fate of people with mental illness depends primarily on the severity of their illness and their treatment rather than on extra-illness factors, such as labels (Huffine & Clausen, 1979; Kirk, 1974; Schwartz, Meyers, & Astrachan, 1974).

A pivotal difference between these perspectives involves the importance of stigma. From a labeling perspective, the stigma attached to the illness is the central problem. A psychiatric label sets into action cultural stereotypes and negative images about mental illness that are applied to the person by others and by the person to themselves (Link, 1987; Link et al., 1987; Link et al., 1989; Thoits, 1985). These negative images devalue those with mental illness and result in discrimination; persons who have mental illnesses are evaluated as "not quite human" (Goffman, 1963, p. 5). Thus, chronic mental illness is a social role, and societal reaction is the most important determinant of entry into that role.

Originally, labeling theory held that the expectations attached to the label perpetuate the mental illness (Scheff, 1966; Scheff, 1974). Scheff's Labeling Model (Figure 2.1A) was later modified to claim that the devaluation and discrimination created by the label interfere with a broad range of life areas, including access to social and economic resources and to general feelings of well-being (Link, 1982; Link, 1987; Link et al., 1987; Link et al., 1989).

The modifications to Scheff's model were further developed by Link and associates (1989). Link's perspective (Figure 2.1B) also relies on the idea that individuals internalize societal conceptions of what it means to be labeled mentally ill. These conceptions include two components, the extent to which people believe that mental patients will be devalued, and the extent to which people believe that patients will be discriminated against. Therefore, patients' expectations of rejection are an outcome of socialization and the cultural context rather than a pathological state associated with their psychiatric condition. As in Scheff's model, both perspectives anticipate that people will perceive community attitudes toward mental illness as negative. Link's model emphasizes the variability in these beliefs and highlights the labeled person's response based on their beliefs about how others will react. Conversely, Scheff emphasizes the responses of others.

Patients receive an official label through treatment contact. As identified by Goffman (1963), patients respond to their status in three possible ways: secrecy, withdrawal, or by educating others. A patient's tendency to endorse these responses indicates that they see stigmatization by others as a threat. A reduction of social interactions and self-esteem may be outcomes that arise directly from the attempts to protect oneself by relying on secrecy and withdrawal. While adoption of these strategies may protect patients from some negative aspects of labeling, they also may limit their lifetime opportunities.

Figure 2.1.A: Scheff's Labeling Approach

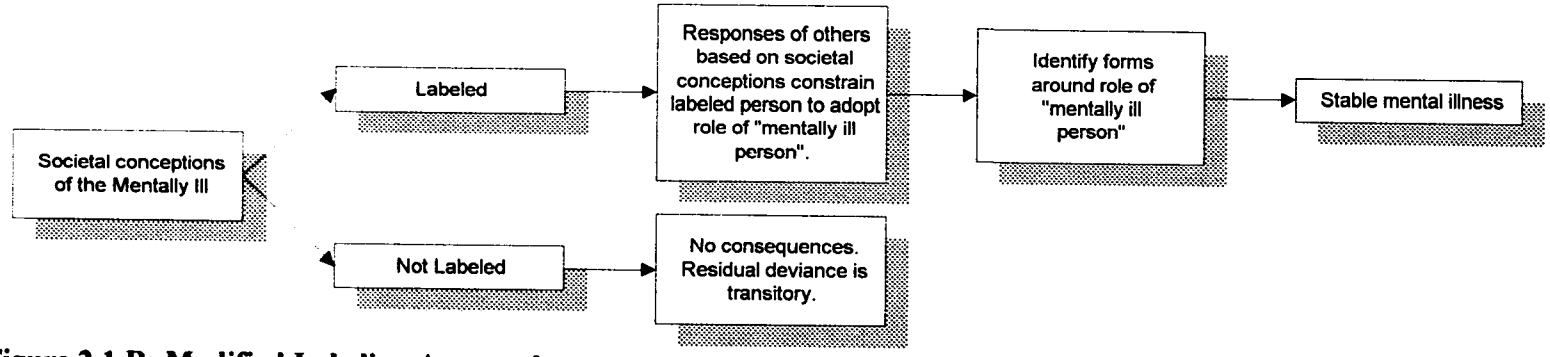

Figure 2.1.B: Modified Labeling Approach

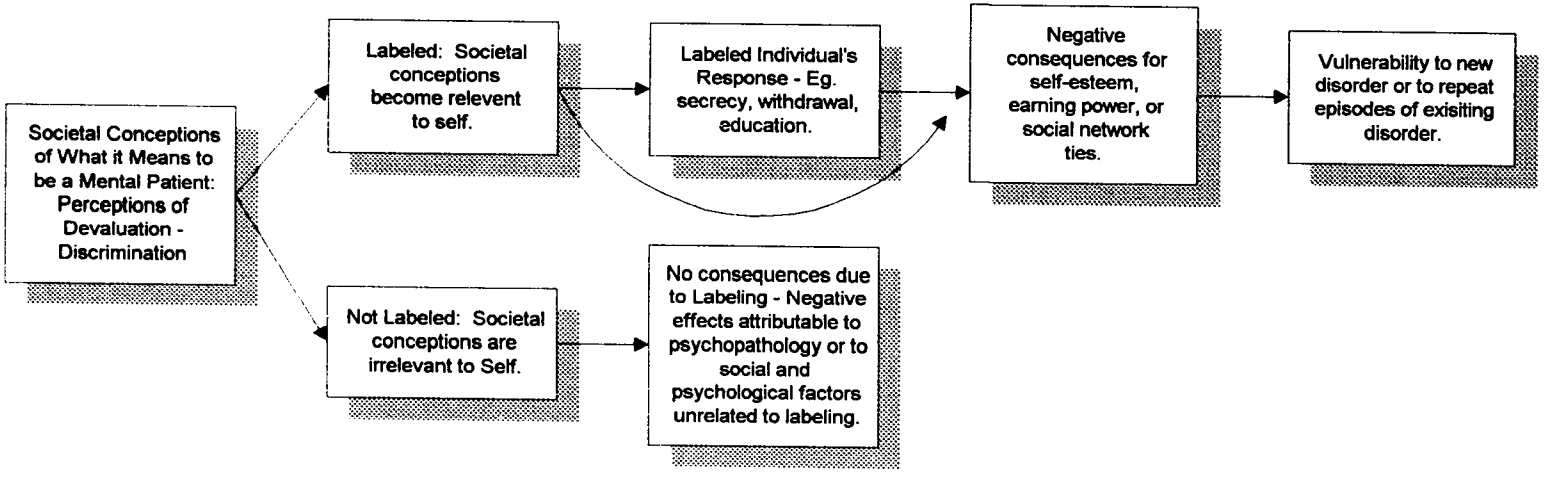

Figure 2.1: Diagrammatic Representation of Scheff's Labeling Model and the Modified Labeling Approach (Link et al., 1989)

If the processes outlined above operate, many patients will lack self-esteem, ties to a social network, and employment because of their own and other's reactions to labeling. These deficits are regarded as major social and psychological risk factors for the development of psychopathology. Unlike Scheff's model, this approach does not assign to labeling the power to create mental illness directly. Instead labeling and stigma are viewed as possible causes of negative outcomes that may place mental patients at risk for the recurrence or prolongation of disorders that result from other causes (Link et al., 1989).

Critics of labeling theory question the claims of both the original and the modified labeling approaches. Perceptions of stigma among mental patients are seen as subjective and untrustworthy or, at the extreme, as distortions resulting from the pathology (Crocetti, Spiro, & Siassi, 1971). Other people are seen to be reluctant to label and stigmatize those with mental illness (Gove & Fain, 1973; Huffine & Clausen, 1979). Thus, stigma is deemed by labeling theory critics to be relatively inconsequential for the mentally ill (Gove, 1970; Gove, 1975). In contrast, critics emphasize that being labeled mentally ill allows people to receive needed treatment. High-quality treatment provides persons suffering from psychiatric disorders with a range of services to improve their symptoms, expand their functioning, and enhances their sense of well being (Gove & Fain, 1973; Linn, 1968).

In summary, the contrasting views of stigma offered by labeling theory and its critics imply opposite effects of psychiatric labels: labeling theorists predict destructive outcomes, while its critics claim beneficial results. Past research has found evidence for both positive and negative effects of labeling; however, this evidence comes from

independent bodies of research. Recently, the direct effects of the receipt of services versus perceptions of stigma were compared on the subjective quality of life for people with chronic mental illness. Results showed that both stigma and services received are independently significantly associated with quality of life, but in opposite ways (Rosenfield, 1997).

2.2.3 Attitudes Towards Mental Illness

2.2.3.1 Background

Mental illness and the psychiatrist have been feared and ridiculed for as long as mental illness has existed. Mentally ill people have been mistreated and loathed (Bhugra, 1989). At their worst, psychiatrists are seen as "crazy", sexually preoccupied, "drug pushers," capable of great good and great harm (Dichter, 1992). Throughout human history, mental illness and the treatment of mentally ill people have been emotional issues reflecting the prevailing situation at the time.

In conjunction with the rise of social psychiatry, a growing concern about the psychiatric patient's social context has emerged. Since the late 1950s, a sizeable body of research concerning the delineation of attitudes towards mental illness had developed. These studies have focused on the attitudes held by the public, mental health personnel, patients, their families, the susceptibility of such attitudes to modification, and the relationship between attitudes and behaviour. A comprehensive review of the literature, from the 1950s and 1960s concerning attitudes towards mental illness has been published by Judith Rabkin in 1972. The following will highlight important historic investigations

and findings that are more recent, and consequently more indicative of the current era of deinstitutionalization and community care.

2.2.3.2 Symptoms, Causes and Treatments

Study of the public's recognition of psychiatrically designated symptoms as mental illness began with a national USA survey in 1950 conducted by Dr. Shirley Star of the National Opinion Research Centre (NORC), University of Chicago. Using a series of vignettes depicting people with psychiatric symptoms, Star found that people generally failed to recognize anything but the most bizarre behaviour as mental illness. The general reaction to the mentally ill was negative and poorly informed. Subsequent studies used, in total or in part, an interview schedule including vignettes illustrating various types of mental illness, developed by Star in her 1950 NORC study. Consequently, an examination of changes in recognition over time is possible. Research by Cumming and Cumming (1957) and D'Arcy (1976) used this approach. A description of their studies is included in the following section.

Recently, the beliefs of several groups of the public were examined regarding the symptoms, causes, and treatments of schizophrenia and compared with those of mental health professionals. The public understood schizophrenia was an emotional disorder marked by irrational fears, depression, and nervousness. They believed schizophrenia was caused by social and environmental factors like stress, emotional trauma, and poor social relations, and was treated with psychosocial methods such as individual psychotherapy and behaviour modification. Such conceptions contrast with those of mental health

professionals, who stressed cognitive disorganization, genetic/biochemical origins, and pharmacological treatment. The public conceptualized schizophrenia along the lines of a "neurotic" disorder, whereas psychiatric professionals characterized it in psychotic/biological terms (Wahl, 1987). The results of this study show that inaccurate ideas about the symptoms, causes, and treatments for schizophrenia are widespread among the public. Implicit in such a finding is the conclusion that mental health professionals have not been successful in educating the public about this disorder.

Help-seeking behaviour and compliance are also affected by attitudes of the patient as well as the public, since they share socialization events. A survey of German citizens showed considerable difference between the conceptions held by the public and those of psychiatric experts regarding the adequate treatment of mental disorders. The public generally held psychotherapy in high esteem, and rejected psychopharmacotherapy (Angermeyer & Matschinger, 1996).

While looking specifically at schizophrenia, psychoanalysis was chosen more frequently from the different forms of psychotherapy. Thus, respondents did not prefer the method recommended by the majority of experts, but precisely that method which, according to experts, was considered inappropriate for the treatment of schizophrenia. Respondents' preference for psychoanalysis was substantiated by the assumption that this method would enable therapists to uncover the causes of the disorder and to eradicate the root of the problem (Angermeyer & Matschinger, 1996).

Fifty percent of the respondents held the view that psychotropic medication allowed only the treatment of symptoms and had no influence on the actual causes of the

illness. Psychotropic drugs were perceived to sedate patients or help them to see everything through rose-colored spectacles without alleviating the underlying problems (Angermeyer & Matschinger, 1996). Two-thirds of the respondents were convinced that patients taking psychotropic drugs run a high risk of becoming addicted (Angermeyer, Daumer, & Matschinger, 1993).

In spite of important advances in the treatment of schizophrenia, many myths and misunderstandings about the disease and its treatment persist. These misunderstandings are largely responsible for the stigma and prejudice affecting those who have had schizophrenia, as well as their families. These myths, range from believing schizophrenia is split personality or multiple personality disorder, to believing schizophrenia is caused by evil spirits or witchcraft. A list of eleven misunderstandings and facts identified by the WPA's *Global Program Against Stigma Discrimination Because of Schizophrenia* and is included in the Appendix A.

2.2.3.3 Social Distance

Measures of social distance have been used to gauge people's willingness to interact with members of potentially stigmatized groups such as people with disabilities, diseases, psychological disorders, or divergent values and lifestyles. The stigmatized are not simply an undifferentiated group of abnormal people, but rather are perceived as having varying grades of offensive characteristics. Social distance scales require respondents to choose one of the responses to reflect the closest relationship you would be willing to have with a member of each target group. Questions asked typically include

would you marry, accept as a close kin by marriage, have as a next door neighbour, accept as a casual friend, and accept as a fellow employee. Using this technique, survey respondents tend to express greater social distance from "deviants" such as drug addicts, alcoholics, the mentally ill and ex-convicts, than from the physically disabled such as paraplegics or the blind (Albrecht, Walker, & Levy, 1982; Sigelman, 1991; Angermeyer & Matschinger, 1997).

2.2.3.4 Mass Media

Social scientists have long been interested in the possible impact of media images on the public's attitudes. Research has indicated that mental illness is frequently depicted in the mass media, particularly the entertainment media. Studies have also shown that these depictions tend to be inaccurate and unfavourable, thus play a significant role in perpetuating harmful misconceptions (Gerbner, Gross, Morgan, & Signorielli, 1981; Steadman & Cocozza, 1977). Those more directly affected by the stigma of mental illness, patients and their families, share this view. In a recent survey about their experiences with stigma, members of the National Alliance for the Mentally Ill consistently cited media sources (particularly films and news stories about mentally ill killers) as primary contributors to mental illness stigma (Wahl & Harman, 1989).

A survey designed to probe American attitudes about mental illness was conducted in 1989 by the Daniel Yanklovich Group, Inc. The survey findings were based on telephone interviews with 1,300 of the public. Results showed that seven of every eight survey respondents (87%) cited television and news programs as a source of information

about mental illness. Newspapers were cited by 76%; radio news, 75%; magazines, 74%; while family and friends were cited by only 51% of the respondents (Robert Wood Johnson Foundation, 1990).

A content analyses of the equivalence of two weeks of prime-time television programming from four major broadcast network affiliates was conducted in 1994. Results showed that the mentally ill are portrayed nearly ten times more violent than other television characters. Television also depicted the mentally ill 10 to 20 times more violent than the mentally ill in the U.S. population over the course of an entire year. In addition, prime-time television portrays the mentally ill as having a negative quality of life and undesirable impact on society. Indeed, the mentally ill are portrayed on television as having a personal life that is more negative than that of violent criminals (Diefenbach, 1997).

The treatment of psychiatric issues in the cinema has received critical attention in the past. One area of filmmaking that was previously neglected, the work of Walt Disney, has recently been examined. Disney's work (e.g., Dumbo, Alice in Wonderland, Mary Poppins, and Beauty and the Beast) is primarily regarded as entertainment for children and is currently available on video to be viewed repeatedly. Given the enormous audience that his films now reach, his art is thought to play a major role in the creation of popular stereotypes. Madness is generally presented in his films as something to fear; something that needs to be shut away. It is seen as the perpetuation of the stock image of madness as a dangerous condition that needs confinement, with society colluding in the labeling and exclusion of those elements that it finds threatening or mystifying (Beveridge, 1996).

2.2.4 Strategies to Reduce Stigma and Discrimination

To reduce the stigma of schizophrenia, it is necessary to (1) change people's attitudes through education and outreach programs, and (2) change public policy and laws to reduce discrimination and increase legal protection for those with mental illness. Specific strategies identified by the WPA's *Global Program Against Stigma and Discrimination Because of Schizophrenia* that can help reduce stigma and improve the quality of life for individuals with schizophrenia include:

- Increased use of treatment strategies that control symptoms while avoiding side effects,
- Initiation of community educational activities aimed at changing attitudes,
- Inclusion of anti-stigma education in the training of teachers and health care providers,
- Improved psycho-education of patients and families about ways of living with the disease,
- Involvement of patients and families in identifying discriminatory practices,
- Emphasis on developing medications that improves quality of life and minimizes stigmatizing side effects.

As previously mentioned, attitudes toward the mentally ill and public recognition of the signs and symptoms of mental illness have been the subject of considerable concern and research. Little has been published about the malleability of public attitudes toward the mentally ill or their effect on patients' social integration. A study of particular interest

is the evaluation of a public education campaign in Saskatchewan by Elaine and John Cumming.

In their book, *Closed Ranks* (1957), the Cummings describe their attempt to change public attitudes toward mental illness through an educational program. The investigators tested residents before and after a six-month educational campaign designed to promote accepting attitudes toward mental illness. They stressed three propositions in their films and group discussions. First, they emphasized that the range of normal behaviour is wider than often believed. Secondly, they stressed that deviant behaviour was not random but had causes that could be understood and modified. Lastly, they emphasized that normal and abnormal behaviour fell within a single continuum so was not qualitatively distinct (Cumming & Cumming, 1957).

The residents readily accepted the first two propositions and went beyond psychiatrists in the range of behaviour regarded as normal. However, the third proposition was so displeasing that the community eventually rejected the entire educational program. The results indicated that the sample feared mental illness and tried to ignore its manifestations; thus, the first proposition was compatible with their outlook. When someone's behaviour became too deviant to overlook, the community wanted the individual to be segregated through hospitalization. To some extent, acceptance of the second proposition provided justification for such action since hospitalization could be regarded as in the interest of the patient as well as the community. The third proposition was disturbing because it suggested that anyone could become mentally ill (i.e., "insane or crazy") under certain circumstances. This idea conflicted with the values of the people of

the community and was ultimately rejected. The Cummings' study demonstrated the negative attitudes toward mental illness, their relationship to a more extensive system of values, and the inability to modify specific attitudes in isolation from its existing system. Cummings' study was replicated in 1976 with no dramatic change found (D'Arcy & Brockman, 1976).

A recent study conducted a census of neighbours' attitudes toward mental illness in two areas before the opening of support houses for the mentally ill. In one area, an educational campaign was conducted. The attitude survey was repeated in both areas and patients' social contacts with neighbours were recorded. Respondents exposed to the educational component of the campaign showed only a small increase in knowledge about mental illness. However, there was a lessening of fearful and rejecting attitudes in the experimental area but not in the control area. Neighbours in the experimental area were more likely to make social contact with improved attitudes. Patients in the experimental area made contact and even friendships with neighbours whereas those in the control area did not (Wolff, Pathare, Craig, & Leff, 1996a).

Prevention of schizophrenia is not currently possible, therefore, attention must be focused on the treatment of the disorder and on the rehabilitation of individuals afflicted with the disease (Sartorius & de Girolamo, 1991). The WPA's *Global Program Against Stigma and Discrimination Because of Schizophrenia* was designed to: (1) increase the *awareness* of the nature of schizophrenia and of treatment options; (2) improve public *attitudes* about those who have or have had schizophrenia and their families; and (3) generate *action* to eliminate discrimination and prejudice (Sartorius, 1997).

2.3 Conceptual Framework

The conceptual framework outlined in Figure 2.2 is based on the review of the literature. In summary, an individual's difference can result in social acceptance and integration or rejection according to culturally developed attitudes. The community's reaction to an undesired deviance will become apparent through the direct actions of its members or it will be indirectly anticipated by the stigmatized individual through common socialization. Stigmatization results from either the expectation of or the enactment of rejection, discrimination and feelings of devaluation. Coping mechanisms ensue which usually involve withdrawal, secrecy, and/or the education of others. The choice of secrecy may extend to deliberately concealing the deviance (passing) or employing subtle strategies to keep the stigma from being overly intrusive in certain interactions (covering). To maintain a sense of self-competence the stigmatized often use conversion as a method of covering. Conversion involves assuming an attribute that is less stigmatizing to minimize adverse reactions.

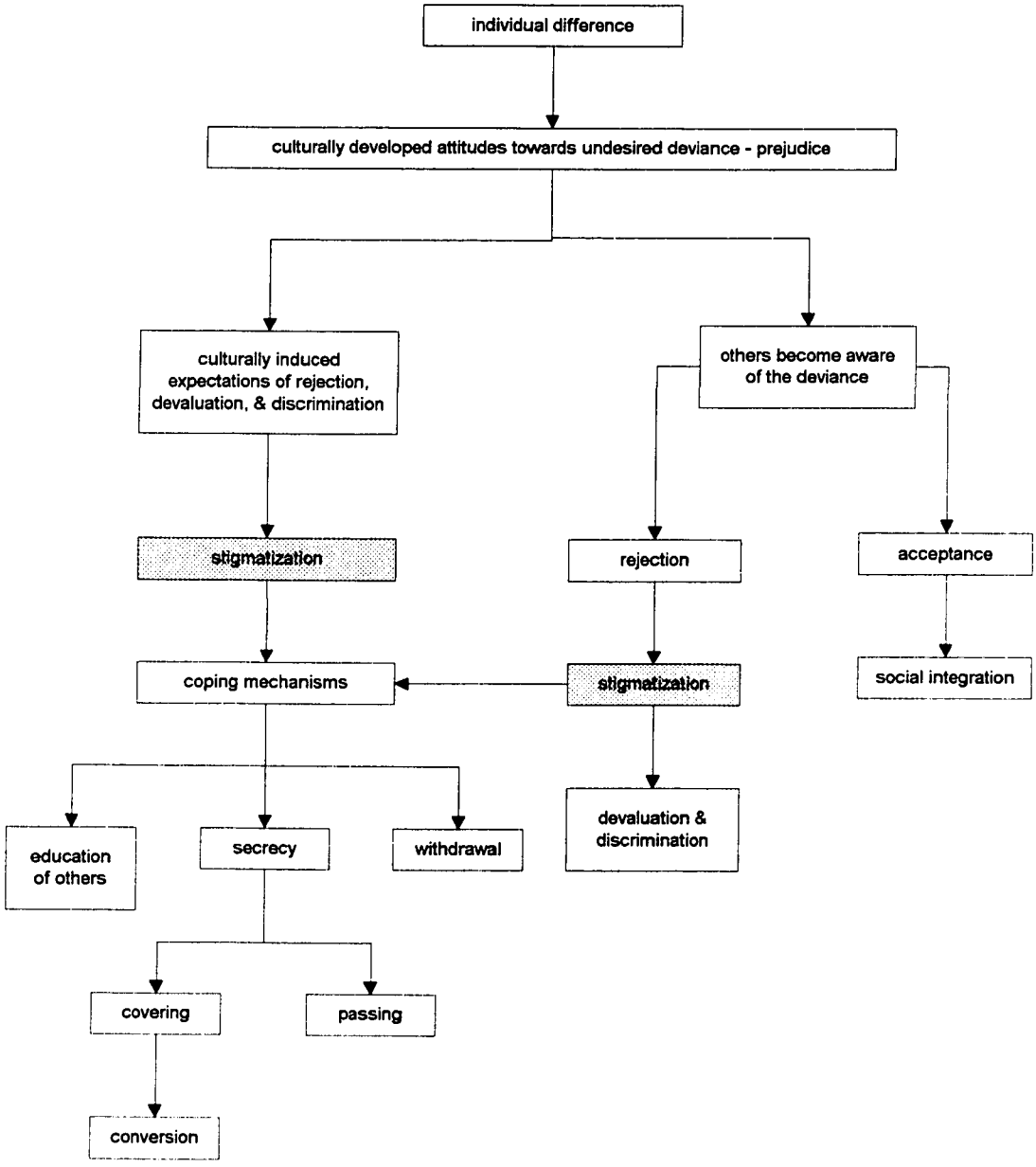

Figure 2.2: Conceptual Framework

CHAPTER THREE: INSTRUMENT DEVELOPMENT

3.1 Introduction

This chapter will describe the methods and results of the first phase of this study, the instrument development. This development phase included a review of the literature, theme identification, item generation, instrument formation, evaluation of content validity and the evaluation of clarity. A study flow chart can be found in Appendix B that summarizes the steps of this study. Results of the pilot testing of the questionnaire on a selected sample of persons suffering from schizophrenia will be presented in Chapter Four.

3.2 Measurement

Stigma, like health, cannot be measured directly. Instead, the process of measurement is indirect. Based on the literature review, it is clear that stigma is multi-dimensional construct. Thus, a single variable that describes stigma does not exist. Instead, its measurement will rely on assembling a number of variables as indicators of stigma, each of which represents an element of the overall construct. Measurement, then, implies the application of a standard scale to each variable, giving numerical scores, which then may be combined into an overall score (McDowell & Newell, 1996). The first step in developing such a scale, and subsequently the questionnaire, was to identify the themes relating to the construct of stigma.

3.3 Theme Development

3.3.1 Introduction

Themes were generated from the published personal accounts and qualitative studies about life experiences of individuals with schizophrenia, and from the concepts identified in the behavioural science literature on stigma. The intent of using qualitative techniques was to tap the experiences of individuals who had schizophrenia in order to depict the "meaning of people's experience toward a phenomenon" (phenomenology), namely stigma and discrimination (Creswell, 1998, p. 38).

Some of the qualitative studies reviewed were based on the experiences of those with a mental illness (not necessarily schizophrenia). The use of data relating to general mental illness is justified as the stigma literature suggests that all mental illnesses elicit similar social responses. Based on the stigma literature, Farina (1998) found that all forms of mental disorders elicited feelings of rejection and degradation and that the feelings intensified with increasingly severe disorders.

3.3.2 Personal Accounts

Thirty-one narratives by individuals with schizophrenia published from 1987 to 1997 were analysed. A systematic review of the journals Schizophrenia Bulletin, Hospital and Community Psychiatry, and Psychiatric Services revealed 28 of these personal accounts. These journals were chosen as data sources because they had a policy of including publication of first person accounts. Two articles that were found during an

additional literature search (Gilmartin, 1997; Anonymous, 1990a) and a book of a first person account (Schiller & Bennett, 1994) were also included in the analysis.

Most (84%) of these written first-hand narratives were primarily obtained from Schizophrenia Bulletin (Anonymous, 1989a; 1989b; 1990b; 1990c; 1990d; 1992; 1994; 1996; 1997; Bayley, 1996; Blaska, 1991; Bowden, 1993; DeMann, 1994; Fleshner, 1995; Fortner & Steel, 1988; Gallo, 1994; Herrig, 1995; Jordan, 1995; Leete, 1989; Molta, 1997; Murphy, 1997; Payne, 1992; Ruocchio, 1989; Stainsby, 1992; Turner, 1993; Wagner, 1996). One narrative was found in each of the following journals: Hospital and Community Psychiatry (Leete, 1987), and Psychiatric Services (Riffer, 1997).

Published personal accounts were recognized as providing an available, vital source of textually rich data. To maintain contemporary perspectives of community care, publications were restricted to those published between 1987 and 1997. The selection strategy used was chosen because of information accessibility.

The process of thematic analysis began with reading the personal accounts and making abbreviated notes around the emergent themes. Repeated readings of these accounts added clarity to the emerging themes.

It is interesting to note that 32% of the authors of these personal accounts choose not to identify themselves. Perhaps this anonymity is another reflection of the stigma felt by those authors, about their mental illness and their experiences.

Themes generated from the analysis of personal accounts were augmented by data from published qualitative studies and local focus group discussions (described in more detail below) about the life experiences of individuals with schizophrenia or a mental

illness.

3.3.3 Qualitative Studies about Life Experiences

The qualitative studies about the life experiences of people with mental illness are differentiated from the personal narratives because the individual stories were synthesized by the authors of these studies; the raw data was not available. The qualitative studies reviewed were categorized into two groups. First, there were individuals' reports about their experiences of schizophrenia (Brekke, Levin, Wolkon, Sobel, & Slade, 1993; Corin & Lauzon, 1994; Cutting & Dunne, 1989; Davidson, 1992; Estroff, 1989; Gara, Rosenberg, & Mueller, 1989; Hooks & Levin, 1986; Kim, Takemoto, Mayahara, Sumida, & Shiba, 1994; Mueser, Valentiner, & Agresta, 1997; Muller & Gunther, 1984; Strauss, 1989; Strauss, 1994; Wciorka, 1988; Windgassen, 1992; Gilmartin, 1997). Secondly, there were reports of experiences of individuals with a mental illness (Gardner, 1991; Goldin, 1990; Hayne & Yonge, 1997; Herman, 1987; Herman, 1993; Lally, 1989; Letendre, 1997; MacDonald & Sheldon, 1997; Lorencz, 1988; Manos, 1992; Okin & Pearsall, 1993; Pugh et al., 1994; Vellenga & Christenson, 1994).

3.3.4 Focus Group Discussions

A focus group is "a discussion in which a small group of informants (six to twelve people), guided by a facilitator, talk freely and spontaneously about themes considered important to the investigation. The participants are selected from a target group whose opinions and ideas are of interest to the researcher" (Willms & Johnson, 1993, In Streiner,

& Norman, 1995, p. 16).

Focus groups were conducted by the Provincial Mental Health Advisory Board (PMHAB) as part of the development of a mental health promotion program (GPC Communications, 1998). The purpose of this program was to change public attitudes and behaviours toward people with mental illness. To accomplish their goals the PMHAB conducted qualitative research to identify those audiences who caused the most stigma toward those with a mental illness and ultimately to identify the audiences to be targeted to educate and influence.

Ten focus group discussions were held across the Province of Alberta (Calgary (4), Edmonton (2), and one each in Wetaskiwin, Ponoka, Grande Prairie, and Medicine Hat) and involved consumers of all ages and their families. Focus group locations were designed to try to get the most inclusive representation of the province as possible. Rural/urban and north/south considerations were taken into account as well as adolescent/adult persons with mental illness and their families. The notes from all focus group sessions were generously provided to the author for inclusion in the theme analysis (GPC Communications, 1998).

3.3.5 Three Themes

Three broad themes were identified from the analysis of the experiential data, supported by previously reviewed theoretical and empirical literature. The first theme regarded prejudice and related to people's discomfort with associating with someone who has a mental illness. The second theme regarded discrimination and the negative actions

taken towards individuals with mental illness. The last theme was coping mechanisms used to prevent rejection and discrimination.

When reviewing the qualitative literature it became apparent that these themes can be differentiated by audience and within audience by situation and sometimes attribute (see Table 3.1) making a template for generating scale items. For example, ease of socialization could be assessed by friends, other people with a mental illness or acquaintances.

Table 3.1: Theme Relationships

Audience	Situation	Attribute
♦ Family or relative ♦ Friend ♦ Individual with mental illness ♦ Acquaintance ♦ Community ♦ Landlord ♦ Educator ♦ Supervisor or employer ♦ Charity organizer ♦ Co-worker ♦ Law enforcement officer ♦ Religious leader ♦ Health care provider ♦ Media personnel	♦ Socializing: ▪ existing relationship ▪ developing relationship ▪ marriage ♦ Getting housing ♦ Sharing housing ♦ Developing housing ♦ Getting work ♦ Volunteering ♦ Working ♦ Getting schooling ♦ Dealing with legal issues: ▪ permits/licenses ▪ ordinance ▪ non-criminal proceedings ♦ Getting care ♦ Being in hospital ♦ Recognizing stigmatized identity ♦ Coping with stigma: ▪ secrecy (passing, covering, conversion) ▪ education ▪ withdrawal	♦ Dangerous ♦ Untrustworthy ♦ Shameful ♦ Discredited ♦ Devalued ♦ Unintelligent ♦ Alienated or avoided

3.4 Stigma as a Construct

As previously outlined (Figure 2.2), the framework used in the development of this questionnaire was based on the notion that socialization leads individuals to develop a set of beliefs about how most people treat individuals with a mental illness. When individuals receive a diagnosis of a mental illness, these beliefs take on a new meaning. The more patients believe that they will be devalued and discriminated against, the more they feel threatened about the possibility of interacting with others. They may keep their treatment a secret, try to educate others about their situation, or withdraw from social contacts that they perceive as potentially rejecting. Such strategies can lead to negative consequences for social support networks, jobs, and self-esteem.

Items relating to secrecy, withdrawal, and education were used to tap coping orientations that individuals with a mental illness might use to deal with stigmatization. The levels at which these strategies are endorsed reflect the threat that is perceived. They are applicable to individuals who have been officially labeled as having a mental illness by contact for treatment (Link et al., 1989).

Therefore, in this conceptualization, stigma is a combination of the perception of being devalued and discriminated against, and the use of coping mechanisms to prevent rejection and discrimination.

3.5 Devising Scale Items

3.5.1 Items from Existing Scales

Although there were a number of scales already in existence, none independently

met the specific needs of this project, or matched closely enough the conceptual framework, which had been developed. It was not possible to combine these scales into a single comprehensive measuring instrument to assess all of the aspects of stigma identified because the scales were devised for other purposes and used different theoretical literature.

The initial process used to devise the scale included looking at what others have done in devising the existing scales. It was valuable to identify what other researchers had deemed relevant, important, and discriminating within the topic of stigma and discrimination. Four instruments served as sources of items.

The first instrument was developed by Link in 1985 (Link, 1987). This scale consisted of 12 items that were written to "assess the extent to which an individual believes most people will devalue or discriminate against a psychiatric patient" (p. 102). The term "devaluation" originated for Link "from Cumming and Cumming's (1965) notion of stigma as 'loss of status' and from Goffman's (1963) ideas about the 'discrediting' nature of a stigma. Closely related was the idea of 'discrimination' as suggested by the extensive 'social distance' tradition" (Link, 1987, p. 97). The items were asked in a six-point "strongly agree" to "strongly disagree" Likert format. The Likert scale requires "the rater to express an opinion by rating his agreement with a series of statements" (Streiner & Norman, 1995, p. 33). The devaluation-discrimination measure showed adequate overall internal consistency (α = .78). Eleven of these twelve items (92%) were modified and used in the first draft of the questionnaire.

The second instrument was designed to measure the endorsement of the coping strategies of secrecy, withdrawal, and education (Link et al., 1989). Three multiple-item measures were written to tap the coping orientations that mental patients might use to deal with stigmatization. The items in these scales were answered with the same six-point Likert format used for the devaluation-discrimination measure. The internal consistency reliability (Cronbach's alpha) of these measures were 0.71 for secrecy, 0.67 for withdrawal, and 0.71 for education. Sixteen of the 17 items (94%) from these three measures were used (intact or modified) in the first draft of the questionnaire.

The third instrument was a measure of discrimination against people with severe mental illness designed by Wahl (1997) as part of the National Alliance for the Mentally Ill's (NAMI) Campaign to End Discrimination Against People with Severe Mental Illness. It was written to determine how people with identified mental illnesses have been treated by others in the community. The instrument consisted of two measures. The first related to stigma and had nine items that were asked in a five-point "never" to "very often" format. The second measure intended to measure discrimination and consisted of 12 items written in a similar format. In total 17 of the 21 items (81%) were modified and used in the first draft of this questionnaire.

Lastly, the fourth instrument was developed to measure the public's knowledge, attitudes, and beliefs about individuals with schizophrenia (WPA, 1998). This instrument was developed as one tool to evaluate the effectiveness of the WPA's *Global Program Against Stigma and Discrimination Because of Schizophrenia*. The six items measuring social distance from this instrument were adapted and included in the stigma scale.

Fifty items that corresponded to the themes relating to stigma and discrimination were considered suitable to be repeated or modified from these previous instruments. One item was modified twice to capture two different subjects.

3.5.2 Newly Developed Items

Existing scales overlooked ten subjects that were identified from the qualitative literature:

- The community's acceptances of developing a group home for the mentally ill in their neighbourhood, or next door.
- The beliefs that people with a mental illness are a danger to themselves or to others.
- The supportiveness of religious leaders to individuals with a mental illness.
- Being treated compassionately when using the hospital emergency room services.
- Being socialized about stigma by mental health care professionals.
- Claiming to have a less stigmatized diagnosis to protect themselves from possible rejection.
- Reluctance to develop new friendships for fear of being rejected because of having a mental illness.
- Ability of people with a mental illness to fit into society.

Thus, 10 new items were developed to reflect these experiences of persons with

schizophrenia or mental illness.

3.5.3 Scale Items

In summary, scale items were developed to elicit information about each theme identified. When available items were adapted from existing instruments measuring related constructs. New items were generated when necessary based on subjective experiences with schizophrenia or mental illness and research or theory. The compilation of items was intentionally over-inclusive to allow for the assessment of different versions of a theme and the subsequent refinement.

The theme regarding prejudice and its associated items are presented in Table 3.2. Similarly, the theme about discrimination and its items are listed in Table 3.3 and the theme regarding coping mechanisms and its items are listed in Table 3.4. Each table maps concepts (appearing in the first column) to potential questions drawn from existing literature or created from qualitative reports (second column). The table also helps to insure that important concepts have not been missed that there is at least one question relating to each important component of the theme.

Table 3.2: Themes and Associated Items Regarding Prejudice

Theme: Prejudice - Others' discomfort with associating with someone who has a mental illness	
Situation or attribute	**Item**
Conversation.	1. I believe most people feel afraid to have a conversation with someone who had a mental illness (WPA, Community survey).
Working.	2. I think most people would be uncomfortable about working on the same job with someone who had a mental illness (WPA, Community survey).
Friendship (version 1)	3. I believe most people would maintain a friendship with someone who had a mental illness (WPA, Community survey).
Living together.	4. I think most people would feel uncomfortable about rooming with someone who has a mental illness (WPA, Community survey).
Friendship (version 2)	5. I believe most people would accept someone who has a mental illness as a close friend (Link, 1987).
Dating.	6. I think most people would be reluctant to date someone who has a mental illness (Link, 1987).
Marriage.	7. I believe most people would marry someone with a mental illness just as they would anyone (WPA, Community survey).
Shame.	8. I think most people would feel ashamed if others knew that someone in their family had been diagnosed with a mental illness (WPA, Community survey).
Community	9. I believe most people in my community, if they knew, would treat someone who has a mental illness just as they would anyone (Link, 1987).
Housing in neighbourhood	10. I think most people would be opposed to having a group home for 6-8 people with a mental illness in their neighbourhood.
Developing housing next door	11. I believe most people would be opposed to having a group home for 6-8 people with a mental illness next door.
Being in hospital Discredited	12. I believe most people think unfavourably of a person who has been in hospital for psychiatric treatment (Link, 1987).

Table 3.2: Themes and Associated Items Regarding Prejudice Continued

Situation or attribute	Item
Dangerous to self	13. I believe most people think that a person who has a mental illness is a danger to himself or herself.
Dangerous to others	14. I believe most people think that a person who has a mental illness is dangerous to others.
Unintelligent	15. I think most people believe that a person who has a mental illness is as intelligent as the average person (Link, 1987).
Untrustworthy	16. I think most people believe that someone with a mental illness is as trustworthy as the average citizen (Link, 1987).
Discredited or devalued	17. I believe most people would take the opinions of someone who has a mental illness less seriously (Link, 1987).
Being in hospital Shameful	18. I think most people believe that if they entered a hospital for psychiatric care it would be a sign of personal failure (Link, 1987).
Getting work - qualified	19. I believe most employers would hire an individual who has a mental illness if he or she was qualified for the job (Link, 1987).
Getting work - trustworthiness	20. I believe most people would not hire someone who has had mental illness to take care of a family member (e.g., child, person with disability, elderly parent) even if he or she had been well for some time (Link, 1987).
Getting work - passed over	21. I think most employers would pass over the application of someone who has a mental illness in favour of another applicant (Link, 1987).

Table 3.3: Themes and Associated Items Regarding Discrimination

Theme: Discrimination – Negative actions taken towards individuals with mental illness	
Situation or attribute	**Item**
Recognizing stigma identity - media	22. I have seen or read thing in the mass media (e.g., television, movies, and books) about people with mental illness, which I find hurtful or offensive (Wahl, 1997).
Recognizing stigma identity - others	23. I have been in situations where I have heard others say unfavourable or offensive things about people who have a mental illness (Wahl, 1997).
Discredited	24. I have worried that others will view me unfavourably because I have a mental illness (Wahl, 1997).
Socializing	25. I have been treated fairly by others who know I have a mental illness (Wahl, 1997).
Devalued	26. I have been advised to lower my expectations for accomplishments in life because I have a mental illness (Wahl, 1997).
Friends	27. Friends who learned I have a mental illness have been supportive (Wahl, 1997).
Discredited	28. I believe I have been treated as less competent by others when they learned I have a mental illness (Wahl, 1997).
Family	29. Family members who learned I have a mental illness have been supportive (Wahl, 1997).
Shunned	30. I have been shunned or avoided by others when it was revealed that I have a mental illness (Wahl, 1997).
Employer Getting work	31. I believe I have been turned down for employment, which I was qualified, when it was revealed that I have a mental illness (Wahl, 1997).
Co-worker or supervisor	32. Co-workers and/or supervisors at work were supportive when they learned I have a mental illness (Wahl, 1997).
Getting housing	33. I have had difficulty renting other housing when it was known that I have a mental illness (Wahl, 1997).
Volunteering -outside mental health	34. I have been excluded from volunteer activities outside the mental health field when it was known that I have a mental illness (Wahl, 1997).

Table 3.3: Themes and Associated Items Regarding Discrimination Continued

Situation or attribute	Item
Volunteering - inside mental health	35. I have been excluded from volunteer activities within the mental health field when it was known that I have a mental illness (Wahl, 1997).
Religious leaders Getting care	36. Leaders within my religious community have been helpful when they learned of my mental illness.
Legal issues - non-criminal proceedings	37. The fact that I have a mental illness has been used against me in non-criminal legal proceedings (such as child custody or divorce disputes) (Wahl, 1997).
Legal issues - ordinance	38. I have been treated fairly by law enforcement officers when they learned I have a mental illness (Wahl, 1997).
Health care provider	39. I have been treated fairly when I have used hospital emergency services for my mental illness.

Table 3.4: Themes and Associated Items Regarding Coping Mechanisms

Theme: Coping mechanisms to prevent rejection and discrimination	
Situation or attribute	**Item**
Medical advise	40. I have been advised by health professionals to conceal my mental illness to avoid rejection and discrimination.
Secrecy -lying	41. I have lied on written applications (for job, licenses, housing, school, etc.) that I had a mental illness for fear that information would be used against me (Wahl, 1997).
Secrecy -diagnosis	42. The best thing to do is to keep my diagnosis of a mental illness a secret (Link et al., 1989).
Secrecy -diagnosis	43. There is no reason for a person to hide the fact that he or she had a mental illness (Link et al., 1989).
Secrecy -treatment	44. I often feel the need to hide the fact that I have had psychiatric treatment (Link et al., 1989).
Secrecy -telling	45. I have avoided telling others outside my immediate family that I have a mental illness (Wahl, 1997).
Advise for relative	46. "If I had a close relative who had been treated for a...mental illness, I would advise him or her not to tell anyone about it" (Link et al., 1989, p. 414)
Getting work	47. In order to get employment I believe that I will have to hide my history of treatment for a mental illness (Link et al., 1989).
Educate others	48. "I've found that it's best to help the people close to me understand what psychiatric treatment is like" (Link et al., 1989, p. 414).
Educate friends	49. If I thought a friend was uncomfortable with me because I had a mental illness, I would try to educate him or her about my illness (Link et al., 1989).
Educate employer	50. If I thought an employer felt reluctant hiring a person who had a mental illness, I would try to explain to him or her that most people with a mental illness are good workers (Link et al., 1989).
Educate public	51. I would participate in an organized effort to teach the public more about mental illness (Link et al., 1989).

Table 3.4: Themes and Associated Items Regarding Coping Mechanisms Continued

Situation or attribute	Item
Educate others	52. After I started treatment for my mental illness, I often found myself educating others about my illness (Link et al., 1989).
Friendship	53. It is easier for me to be friendly with people who have or had a mental illness (Link et al., 1989).
Withdrawal	54. If I thought that someone I knew held negative opinions about people with a mental illness, I would try to avoid them (Link et al., 1989).
Getting work -withdrawal -form	55. If I was looking for a job and received an application, which asked about a history of psychiatric treatment, I would complete it (Link et al., 1989).
Getting work -withdrawal -application	56. If I thought an employer was reluctant to hire a person with a history of a mental illness, I wouldn't apply for the job (Link et al., 1989).
Avoidance	57. If I believed that a person I knew thought unfavourably about me because I have a mental illness, I would try to avoid him or her (Link et al., 1989).
Conversion	58. I have claimed to have a different diagnosis so to protect myself from possible rejection.
Covering	59. "When I meet people for the first time, I make a special effort to keep the fact that I have been in psychiatric treatment to myself" (Link et al., 1989, p. 414) .
Developing relationship	60. I am reluctant to develop new friendships in fear of being rejected because I have a mental illness.
Socialization	61. Individuals who have had a mental illness are able to fit into society.

3.6 Instrument Formation

Clinical experts with extensive research and clinical experience indicated that the scale should take the form of a paper-and-pencil questionnaire that was brief, easy for chronically ill populations to complete, and potentially amenable to computer administration and scoring. In addition, an attempt was made to keep the questionnaire simple, interesting, and non-threatening (Woodward & Chambers, 1983).

3.6.1 Scaling Responses

A technique called direct estimation was used to quantify the judgements of the subjects on these items. Direct estimation methods are "designed to elicit from the subject a direct quantitative estimate of the magnitude of an attribute" (Streiner & Norman, 1995, p. 32). The approach involved asking respondents to express an opinion on a three-point Likert-type scale (DeVillis, 1991) composed of three response options: "agree", "disagree", and "not sure".

This estimation method, being a simple and easy to administer response option was considered most appropriate for a population that may suffer from perceptual and cognitive deficits. More complex methods, such as comparative methods, and econometric methods were not used in light of mental health professionals having identified the need for a scale that was exceedingly simple and straightforward to complete (Streiner & Norman, 1995).

3.6.2 Response Bias

The ease of design and administration is both an asset and a liability; because the intent of questions framed on a rating scale is often obvious to both the researcher and respondent, bias in response can result.

"Acquiescence bias or yea-saying is the tendency to give positive responses" (Streiner and Norman, 1995, p. 78). At its most extreme, the person responds positively irrespective of the content of the item. At the opposite end of the spectrum are the "nay-sayers". It is believed that this tendency is normally distributed, so that relatively few people are at the extremes, but that many people exhibit this trait to lesser degrees. The usual way to correct for this potential bias is to have an equal number of items keyed in the positive and negative directions (Streiner & Norman, 1995). In this case only 10 items (26%) were reversed (items #10, 17, 26, 27, 29, 33, 37, 38, 39, 41). While trying to keep the wording simple, it was felt that only 10 items could read easy in the reverse direction.

3.6.3 Demographic Variables

The collection of descriptive information about respondents is common in surveys. Variables such as age, gender, marital status, employment status, education, and religious affiliation are used to evaluate the representativeness of the study sample and to cross-tabulate responses of survey items. These variables were used in this survey, as well as questions about age of onset of schizophrenia, frequency and duration of hospitalization, and if subjects had been formally committed.

By convention the term "item" will be used to refer to a statement in a scale and

the term "question" will refer to examination of demographic variables (McDowell & Newell, 1996).

3.6.4 Draft One of the Questionnaire

The 61 scale items were grouped in the questionnaire by the following in three themes: prejudice (21), discrimination (20), and coping mechanisms (20). Questions regarding social economic variables (28) were developed and assembled into the first draft of the questionnaire (Appendix C).

3.7 Evaluation of Content Validity

3.7.1 Terms

Preliminary evaluation of the questionnaire began with the assessment of content validity. The validity of an instrument is the extent to which it measures what it is supposed to measure. Content validity focuses on the representativeness or sampling adequacy of the content (substance, matter, and topics) of the measuring instrument (Berger & Patchner, 1988).

3.7.2 The Expert Panel

The content validity of the questionnaire was determined by the judgement of a panel of 22 experts. The panel was comprised of nine professional researchers or clinicians, seven mental health service administrators, four consumers or consumer group representatives, and two industry liaisons. Four members of this group either had

schizophrenia, or had a family member with schizophrenia. Nineteen members of the expert panel are currently involved in the WPA's *Program Against Stigma and Discrimination Because of Schizophrenia.*

All members of the Local Action Committee of the WPA's Global Program and four other experts in the field were also asked to participate. Members attending the WPA's Local Action Committee meeting in December 1998, were asked to participate in this evaluation. Each member received a covering letter, questionnaire, and a form to summarize their responses. Members of the committee not present at the meeting and panellists external to the committee either received the materials by mail or by hand. Experts, external to the Local Action Committee, were asked in advance of receiving the materials if they would be willing to participate. Panellists who had not responded by early January received a telephone call or email encouraging their response.

The overall response rate of 75.9% was obtained (N=29). As shown in Table 3.5 the response rate was 80% or more amongst the professional researchers and clinicians, the health service administrators and the consumers or consumer groups representatives. The lowest proportion of responses was from the industry liaisons, particularly the pharmaceutical industry.

It was expected that the evaluation by representatives of the pharmaceutical industry would supplement insight on treatment acceptability. The under-representation of the pharmaceutical industry on the expert panel does not pose a threat to the integrity of this evaluation because views about treatment were common to clinicians, consumers, and consumer representatives and representation from these other groups was good.

Table 3.5: Summary of Expert Panel Contacts and Responses

	Professional Researcher or Clinician	**Mental Health Service Administrator**	**Consumer or Consumer Group Representative**	**Industry Liaison**
Distributed	10 (34.5%)	8 (27.6%)	5 (17.2%)	6 (20.7%)
Responded	8 + 1 verbal (90%)	7 (87.5%)	3 + 1 verbal (80.0%)	2 (33.3%)

Overall response rate: (22/29) 75.9%

These experts rated the content for relevance to the concept of felt stigma (whether all items were relevant to the scale's purpose) and comprehensiveness (whether all aspects of felt stigma have been successfully addressed by the scale items). They also reviewed the formatting for clarity and ease of administration. Items and formatting were revised based on the comments received.

3.7.3 Comments

The comments provided by the expert panel were extensive. Thus, they have been summarized in Appendix D. As shown in Table 3.6, the comments from the expert panel resulted in significant revisions: 33 items and eight questions (41 in total), the deletion of 25 items and 16 questions (41 in total), the addition of three items and three questions (six in total), and the retention of three items and four questions without change.

Fifty-two percent of all the decisions for revision, deletion or addition, were based on the input of the professional researchers or clinicians, 21% by mental health administrators, 6% by consumers or consumer group representatives, 10% by industry liaisons, and 11% by the author. The proportions of all the comments made which warranted action was as follows: 57% by the professional researchers or clinicians, 24% by the mental health care providers, 52% by the consumers or consumer group representatives, and 47% by the industry liaisons warranted action.

Table 3.6: The Number of Item or Question Revisions, Deletions and Additions Resulting from the Evaluation of Content Validity

Category	Number of Items or Questions					
	Draft 1					Draft 2
	Original	Revised	Deleted	Unchanged	Added	
Prejudice	21	13	7	1	0	14
Stigma socialization*	0					4
Discrimination	20	15	3	2	3	16
Coping mechanisms	20	5	15	0	0	5
Demographics	28	8	16	4	3	15
Total	89	41	41	7	6	54

*Stigma socialization was a new theme identified during the review by the expert panel. The four items within this theme were previously categorized as items regarding discrimination.

3.7.3.1 Revisions and Deletions

More items were generated than was ultimately planned to be included in the scale. To avoid measurement error, items that did not contribute greatly to the purpose of the scale as judged by the expert panel were deleted. This would ensure that scale would not discriminate among subjects on a dimension that was irrelevant to the main topic of interest. The revisions and deletions are outlined below according to theme.

3.7.3.1.a Prejudice

Revisions within the category of prejudice included minor changes in wording, such as switching the phrase "*rooming with*" to "*living with*". Other revisions were intended to simplify the choice of words. Two examples of this type of revision include: (1) "*have a conversation with*" was changed to "*to talk to*", and (2) "*be reluctant to date*" was changed to "*not date*".

The first draft of the questionnaire included a number of items that were considered to be close in meaning. The intent was to assess both versions to determine if the experts would express a preference between the two, and to ascertain whether the distinction between items warranted including them both. Two examples of this strategy, within the category of prejudice are: (1) item #23 and 24: "*...opposed to having a group home for 6-8 people who have a mental illness in their neighbourhood*" and "*having a group home for 6-8 people with a mental illness next door*"; and (2) item #26 and 27: "*...a person who has a mental illness is a danger to themselves*" and "*...is dangerous to others.*" In total, six pairs of items were reviewed. In each set, one item was retained and

the other deleted. The expert panel suggested that, with the need to keep the questionnaire short in length, similar items needed to be reduced.

3.8.3.1.b Discrimination

Within the category of discrimination, four items were identified as being distinct from the nature of the other statements. These items were regrouped in a new category called stigma socialization. Two of these items (#35 and 36) were revised to include a temporal orientation. The other two (#39 and 44) were revised to improve the clarity of the items.

Five additional revisions, within the category of discrimination, were made to simplify the choice of words or to shorten the total word count of the item. An example of this is item #43. The original version of the item was *"I have been shunned or avoided by others when it was revealed that I have a mental illness"*. This was revised to *"I have been shunned or avoided by others because I have a mental illness"*. Inconsistencies in the structure of two items and an error in grammar in one item were also corrected. The expert panel identified two items in the questionnaire that were too broad in their focus and were deleted. An example, within the topic of discrimination was item #38 *"I have been treated fairly by others who know I have a mental illness"*.

3.8.3.1.c. Coping Mechanisms

The total number of items regarding coping mechanisms was considerably reduced. Three subjects, secrecy, education, and withdrawal were tapped in this segment. The

expert panel noted that the distinction between the items within each subject, were too narrow, making this portion of the questionnaire confusing. Consequently, thirteen of the original twenty items were deleted.

The following three items demonstrate this narrow distinction in subject matter: #55 – *"The best thing to do is to keep my diagnosis of mental illness a secret"*; #56 – *"There is no reason for a person to hide the fact that he or she had a mental illness"*; and #57 – *"I often feel the need to hide the fact that I have had psychiatric treatment"*. In this case item #55 was retained (with revision) and items #56 and 57, and two additional items within this theme were deleted.

Three items within the theme of coping mechanisms were revised to report rather than predict behaviour. This change was made to improve the reliability of the data. Continuing with the same example, item #55 was revised to *"I keep my diagnosis of mental illness a secret to prevent rejection"*.

One item (#66) in this grouping was identified as not being a coping mechanism. Another item (#74) was deemed not appropriate for the intended purpose of this questionnaire. Both these items were deleted.

3.8.3.1.d Demographic Information

In the final section, demographic information, thirteen questions were deleted because they were considered unnecessary, redundant, or inappropriate for the intended purpose. For instance, a number of questions required the respondent to estimate the duration of treatment in hospital (item #8) or as an outpatient (item #12), and the number

of times they were admitted to hospital voluntarily (item #7) or involuntarily (item #10). These four questions were deleted because they were considered too difficult for the respondent to recall and estimate.

Three revisions were made to improve the accuracy of the demographic information desired. For example, the objective of item #3 was to estimate the duration of their mental illness. The original question asked, *"What age were you when you were diagnosed with a mental illness"*? The revised question asked, *"What year did you begin psychiatric treatment"?* In addition, four questions were simplified or combined in this section. These questions related to the highest level of education achieved.

3.7.3.2 Additions

Expert opinion also proved to be an important source of scale items. Since an attempt was made to obtain a balanced cross-section of experts in this topic area, their opinions were thought to represent the most recent thinking in the area.

The process of evaluating content validity involved identifying any important areas that were missed. Members of the expert panel were requested to suggest an additional item to fill such a gap. Six new items or questions were generated in this process. The clinical observations of four psychiatrists served as the basis for additional items. Three items and three questions were pooled from their comments and incorporated into the second draft of the questionnaire. These additions included the following scale items and demographic questions:

1) General health care providers have been supportive when I revealed I have a mental illness.
2) Teachers and instructors have been supportive when I revealed I have a mental illness.
3) I have been denied acceptance into school or education programs when I revealed I have a mental illness (Wahl, 1997).
4) Are you currently receiving care for a mental illness?
5) If yes, did you stay in a...? Mental hospital, psychiatric ward in a general hospital, or non-psychiatric ward in a general hospital.
6) Have you worked consistently for the past three months?

3.7.3.3 Format

Generally, the questionnaire format was considered appropriate, however the length was viewed as too long. This is not surprising given our attempt to remain over-inclusive and provide panellists with question alternatives.

3.7.3.4 Response Options

Concern was noted regarding the number of response choices and the selection of adjectives. Three response levels were used for items regarding prejudice and coping mechanisms. The adjectives used were "agree," "disagree", and "not sure". Members of the expert panel were concerned that the option "not sure" would be over-used. They recommended the use of a four or five point scale without the option "not sure".

In addition, a number of approaches, identified in the literature, were adopted in the second draft of the questionnaire to maximize precision and minimize bias as addressed by the expert panel. The first approach related to the number of steps or boxes on a scale. The goal is to have as many levels as the respondent is able to discriminate between. If the number of levels is less than the respondent's ability to discriminate (as in the first draft), the result would be a loss of information.

Although the ability to discriminate might seem to be contingent on the particular situation, there is evidence that this is not the case. Nishisato and Torii (1970) showed that reliability coefficients drop as fewer categories are used. Results from this study suggest that the minimum number of categories used by respondents should be in the region of five to seven. Additional evidence exists that in a variety of tasks, people are unable to discriminate much beyond seven levels. Thus, it is reasonable to presume that the upper practical limit of useful levels on a scale can be set at seven (Aday, 1996; Streiner & Norman, 1995).

The next issue related to whether there should be an even or odd number of categories. The revised scale regarding issues of prejudice used a bipolar rating system, definitely agree - definitely disagree. The provision of an odd number of categories allows respondents the choice of expressing no opinions. Conversely, an even number of boxes forces the respondents to commit themselves to one side or the other (Streiner & Norman, 1995). The portion of the scale dealing with prejudice was limited to four categories, whereas the remainder of the scale used five. Recognizing that a degree of error would be introduced by forcing individuals who had a neutral opinion to choose between agreeing

and disagreeing, it was thought that the added information would be a benefit to the precision of the scale. Thus, the response options were revised to "definitely agree", "agree", "disagree", and "definitely disagree" for items concerning prejudice, and "never", "seldom", "sometimes", "often", and "always" for items about coping mechanisms. Similarly, the options regarding discrimination were changed from "does not apply", "never", "sometimes", and "often" to "does not apply", "never", "seldom", "sometimes", "often", and "always".

3.7.4 Draft Two of the Questionnaire

The second draft of the questionnaire had a total of 39 items and 15 questions (from an original 89 items or questions): prejudice – 14 (from 21); stigma socialization – 4 (from 0); discrimination – 16 (from 20); coping mechanisms – 5 (from 20); and demographics – 15 (from 28). The revised questionnaire (draft #2) is contained in Appendix E.

3.8 Evaluation of Clarity

3.8.1 The Masters Student Panel

To obtain opinions about the clarity of the instructions and items, the Masters Students within the Department of Community Health Science reviewed the revised questionnaire (Draft #2). The 37 Masters Students each received an email and letter requesting their participation and a questionnaire. One follow-up email was sent to encourage participation if a response was not received within one week. Eighteen Masters

Students evaluated the questionnaire for clarity, giving a response rate of 48.6%.

3.8.2 Instructions

The Masters Students were asked to review the questionnaire to ensure that the items:

- included words or terms that would be simple, direct, and familiar, to the target population,
- were clear, specific, and as short as possible,
- did not contain double negatives,
- were not too demanding and did not assume too much knowledge,
- were not leading, biased or objectionable, and were applicable to all respondents, and
- provided an appropriate time referent, contained response categories that were clear and mutually exclusive, and answers that would not be influenced by the response styles.

Lastly they were asked to consider the length and flow of the questionnaire, and whether it included appropriate and clear instructions and skip patterns.

3.8.3 Comments

The Masters Student Panel provided a fresh look at the first revision of the questionnaire. Their strengths were their knowledge in health research methods and

expertise in a variety of fields within the health care field. Their evaluation identified a number of errors in the question or item structure, such as double purposes within one item, and non-mutually exclusive response choices. Their comments were beneficial to the second revision of the questionnaire. A summary of the comments is provided in Appendix F.

As shown in Table 3.7, the comments from the Master Students resulted in significant revisions: 26 items and 13 questions (39 in total), leaving 13 items and two questions unchanged (15 in total).

Table 3.7: The Number of Item or Question Revisions Resulting from the Evaluation of Clarity

Category	Number of Items or Questions			
	Draft 2			Draft 3
	Original	Revised	Unchanged	
Prejudice	14	6	8	14
Stigma socialization	4	3	1	4
Discrimination	16	13	3	16
Coping mechanisms	5	4	1	5
Demographics	15	13	2	15
Total	54	39	15	54

3.8.3.1 Revisions

The rationale for the revisions was grouped into 12 categories and was summarized in Table 3.8. Twenty-three percent of the 39 revisions focused on simplifying the choice of words. Examples of these changes include: *"advised"* to *"told"*; *"conceal"* to *"hide"*; *"learned"* to *"know"*; and *"when I revealed"* to *"know"* or *"told them"*. The other two large contributors to the revisions were adding more detail to improve the accuracy of the question (15%), and improvements in wording (15%). For instance, question #3 was revised to include examples of what was intended by the phrase *"receiving care for a mental health problem"*. The examples given were *"care from psychiatrist, a family doctor, or a professional at a mental health clinic"*. An improvement in wording included a change like (item #17) *"I think most people would believe that a person who has a mental illness is intelligent"* to *"I think most people would believe that a person who has a mental illness can be intelligent"*.

The sentence structure for four items was reorganized to improve reading flow. Another four items were revised to simplify and shorten the statements. An example that included both these reasons is item #16. The original statement was *"I think most people would be against having a group home for 6-8 people who have a mental illness in their neighbourhood"*. It was revised to *"I think most people would be against a group home in their neighbourhood for people who have a mental illness"*.

Table 3.8: Summary of Revisions Based on the Evaluation of Clarity

Revision Category	Item or Question Number (Based on Draft #2)					Total (%)
	Prejudice	Stigma Socialization	Discrimination	Coping Mechanisms	Demographics	
Format	14, 18				1	3 (6)
Use more familiar phrase					2	1 (2)
Added detail to improve accuracy	20				3, 5, 47, 50, 52, 54	7 (15)
Response options not mutually exclusive					6, 47, 52	3 (6)
Add "other (please specify)" response option					6, 48, 49, 54	4 (9)
Simplify wording	10, 18	24, 25	26, 27, 28, 29, 30, 37, 39			11 (23)
Improve word choice	17		35, 40	42, 46	4, 53	7 (15)
Reorganize sentence	16	22	28, 30			4 (9)
Simplify sentence	16		31	43, 44		4 (9)
Grammar			34			1 (2)
Double question			33			1 (2)
Improve consistency			41			1 (2)

One item (#33) was identified as being a dual question, having two distinct parts. This item involved assessing whether co-workers and/or supervisors at work were supportive to the individual with a mental illness. Since it is possible to have co-workers that were supportive at the same time, as supervisors who were not supportive (or vice a versa), one portion of the question was deleted. The revised item focused on the individual's experience with their supervisor.

Within the questions regarding demographic information, three questions were identified as having responses that were not mutually inclusive. In two cases, the option to *"check as many responses as applied"* was provided. Question #6 illustrated the need for this type of revision: *"Did you stay in a mental hospital, a psychiatric ward in a general hospital, or a non-psychiatric ward in a general hospital"*? Someone could have stayed in one, two, or all three of these settings. In addition, four questions were revised to include the opportunity to describe another response that was not already identified. Including a check box for *"other"* and asking the respondent to specify the details achieved this.

The clarity of five items (#11, 37, 38, 39, and 43) and one question (#7) was queried. These questions were essentially retained intact with the intent of evaluating the concerns during the pilot test. The respondent would be asked:

1) Whether being hospitalized "against your will or involuntary" was interpreted as being committed under the Provincial Mental Health Act (question #7)?

2) Who was included in the group of "most people" when they assessed whether "most people would feel uncomfortable living with someone who has a mental illness" (item #11)?

3) Who was included in the grouping of "general health care providers" (item #37)?

4) Whether the word "fairly" adequately covers the feelings of being treated courteously, respectfully, as a person by the nurses and doctors in emergency services (item #38), or by law enforcement officers (item #39).

5) What the respondent tries to hide, if they were to "hide any visible signs" of their mental illness (item #43).

Revisions were made for the use of arrows and the choice of words for one directional box to improve skip patterns. The adjectives used in the response options for the scale items within the category of prejudice were again revised. The adjectives included "definitely agree", "agree", "disagree", and "definitely disagree". They were changed to "strongly agree", "somewhat agree", "somewhat disagree", and "strongly disagree" to use terms that were considered more common and more appropriate responses for the given statements. To avoid potential confusion between the two similar words "seldom" and "sometimes", the response adjective "seldom" was replaced with "rarely". Finally, many of the preambles were revised to decrease wordiness.

3.8.3.2 Format

Additional comments by the Masters Students indicated that the questionnaire was a good length, easy to read and understand. It had a good flow and its purpose was clear. The questions were thought to be clear, concise, relevant, brief, and interesting. The arrows were effective for skipping and the instructions were clear and easy to follow.

3.8.4 Draft Three of the Questionnaire

Based on the above changes the third draft of the questionnaire had the same number of items and questions as draft two of the questionnaire. The revised questionnaire was considered appropriate for pilot testing with a selected sample of people with schizophrenia. The details of this testing are described in the following chapter. The revised questionnaire (Draft Three) is contained in Appendix G.

CHAPTER FOUR: PILOT TEST

4.1 Introduction

This chapter will summarize the methods used in sampling, data collection and management, data analysis and the respective results of the pilot test. The pilot test was intended to evaluate the content, feasibility of administration (including acceptability and clarity), and the interpretability of the data, in a small and selected sample of individuals diagnosed with and receiving treatment for schizophrenia.

4.2 Sampling

4.2.1 Exclusion and Inclusion Criteria

Subjects needed to be 18 - 65 years of age. Each subject was required to understand the nature of the study and voluntarily sign an informed consent. Each subject had received a clinical diagnosis of schizophrenia according to the DSM-IV or ICD-10 criteria (see Appendix H). Subjects were excluded if they were seriously ill or incompetent to provide informed consent as judged by a key contact or if they were unable to speak or comprehend English.

4.2.2 Sample Size

The aim of this study was to administer the revised scale to 10 - 15 subjects. Although no consensus exists on sample size for instrument development and testing (Goering & Streiner, 1996; Kuzel, 1992), it was expected that this number would be

sufficient to highlight the most salient problems and deficiencies with the questionnaire.

4.2.3 The General Sampling Approach and Rationale

Individuals with schizophrenia were chosen to be subjects because they are among those at highest risk of experiencing psychiatric stigma and among those who would have the most difficulty completing questionnaires.

4.2.4 The Sample

Seventeen volunteers who had been clinically diagnosed with schizophrenia and were either attending a day hospital program or were members of a local consumer association participated in the pilot evaluation. Nine (53%) were recruited from the Psychiatric Day Program at the Peter Lougheed Centre and eight (47%) were recruited from the membership of the Calgary Chapter of the Schizophrenia Society of Alberta.

4.3 Ethical Considerations

The proposal received approval from the University of Calgary's Conjoint Health Research Ethics Board and the Research and Development Committee for the Calgary Health Region.

There is often the perception that individuals who suffer from psychotic events are unable to provide informed consent. The capacity of individuals with schizophrenia is variable. In order to meet ethical approval this study was designed to not target seriously ill individuals and individuals who would not be competent to provide informed consent as

judged by key contacts.

A two-step procedure was used to obtain informed consent. In this first step, potential subjects were advised of the study either in a group forum or personally. Interested subjects completed the preliminary consent form, which were reviewed for inclusion and exclusion criteria by the key contact. The involvement of knowledgeable key contacts ensured that seriously ill or incompetent subjects were not approached to be part of this research, and that subjects had given permission to be approached. (See Appendix I for the Preliminary Consent Form.)

During the second step, the investigator reviewed the formal consent form with the potential subject (Appendix J). This review outlined the nature of the study, their participation, how data would be handled and protected, study risks, and study benefits. Interested subjects were asked to read the formal consent form before signing.

Names were not included on the questionnaire or in the study's database. The data are being kept strictly confidential under separate lock and key in the research office of the Investigator. Access to the raw data is restricted to the research team.

4.4 Data Collection and Management

Once informed consent was obtained, the questionnaire containing the revised scale and other relevant demographic variables was provided to each subject. Subjects completed the questionnaires individually or in pairs, then provided their completed questionnaires and verbal comments to the investigator.

Survey questionnaires were manually coded, entered into Microsoft® Excel 97 for

Windows, and checked to ensure accuracy.

4.4.1 Time Commitment

Participation in the pilot study usually took 25 minutes. It involved reviewing the details of the study for the consent process, completing the questionnaire, responding to the six items identified previously in the evaluation of clarity, and offering general comments. Most participants (73%) took eight to 12 minutes to complete the questionnaire. However, on two occasions the entire process took sixty to ninety minutes. In these two cases, the participants were eager to share their experiences with stigma and discrimination with the investigator.

4.4.2 Requests for Clarification

While completing the questionnaire, clarification was requested by the subjects on several key issues. For example, they wondered if: (1) employment included volunteer work (question #51); (2) whether siblings meant brothers and sisters (question #48); and (3) whether rented housing included an apartment or basement suite (question #48). Similar confusion on these questions was noted through either written comments on the questionnaire or by the responses themselves while cleaning the data.

4.5 Data Analysis

4.5.1 Overview

The following section outlines the cleaning of the data including the management

of missing data and a description of two subjects who were predominantly responsible for the missing items. It also includes the analyses of the distribution of responses with respect to variability and skew for each theme or subscale. As well, the opinions of the subjects regarding content and clarity are summarized. Lastly, the procedure used for scoring and the distribution of scores are described, in addition to background theory of scale interpretation.

4.5.2 Data Preparation

Data cleaning refers to "the process for detecting and correcting errors" (Aday, 1996, p. 313). Three steps were taken to ensure the data was clean. Each completed questionnaire was reviewed and coded by the investigator. Inconsistencies in responses were noted. Entries into the computer database were checked manually and errors were corrected. Lastly, non-responses were assessed for the impact on the validity of the scale.

4.5.2.1 Editing Responses

Nineteen changes in the subjects' responses were made in a total of 12 completed questionnaires. Each questionnaire was reviewed before entering results into the database. Responses to questions or items that were supported by qualifying notes written by the subjects were reviewed to ensure their response was the most suitable. In addition, questions that involved skip patterns were reviewed to ensure consistency in the subject's responses. These revisions are described below in more detail.

Question #50 regarding the highest level of formal education elicited six of these corrections (32%). In four cases, dual responses were provided (subjects #4, 11, 14, and 15). Each time *"studies after high school (no degree or diploma)"* was checked in addition to completing *"less than high school"* on two occasions and graduating high school on the other two occasions. Priority was given to the choice *"less than high school"* when that option was used in combination with *"studies after high school (no degree or diploma)"*. In the second case, priority was given to *"studies after high school (no degree or diploma)"* when used in combination with *"high school graduate"*.

The remaining two corrections were based on qualifying statements written on the questionnaire by the respondent. In the first case, the subject indicated she had completed one year of university but had only checked the response indicating the highest level of education achieved was high school. The more appropriate response was "studies after high school (no degree or diploma)". The subject in the second case edited her response to read "college degree". This response was revised to "university degree." In turn, this question was revised.

On five occasions (26%), subjects chose the "other" option and provided a detailed answer. Modifications made to responses of this type involved question #49, regarding type of accommodation, four times (subjects #1, 2, 3, and 13) and question #54, regarding being unemployed and looking for work, once (subject #14).

The next set of adjustments was generated when a series of related questions were asked and an inconsistency was observed. In four cases (subjects #1, 5, 13, and 14), an inconsistent response was given in the series of questions regarding employment. This

series asked the following questions: #51 – "*Are you currently employed?*" #52 – If yes to #51, "*are you employed full-time or part-time*?" #53 – If yes to #51, "*have you worked regularly for the past three months*?" An example of an inconsistency would be responding that you worked part-time regularly for three months, but qualified the answer with "volunteer work" (subject #8). In this situation, the response to question #51 was coded as being unemployed.

The second series of questions that involved an inconsistency was the set #3, 6, and 7. This series regarded receiving care for a mental illness. The one time a discrepancy was noted involved the following scenario. The subject (#5) indicated that she had never received care from a psychiatrist, a family doctor, or a professional at a mental health clinic for a mental health problem (question #3). However, she did indicate that she had stayed in hospital to receive treatment for a mental illness (question #5), specifically at a psychiatric institution, a psychiatric ward in a general hospital and at a non-psychiatric ward in a general hospital (question #6). In this case, the response for question #3 was coded as yes.

The final three edits were made when the respondent provided more information as a qualifying statement to their response. In one case (subject #1), the respondent edited the question (#40) to read "criminal disputes" instead of "non-criminal disputes". In this case, the response was coded as a missing item.

4.5.2.2 Missing Items

A frequent problem with data collection using scales is missing data. Respondents

can fail to complete items within a scale either intentionally or unintentionally. Missing data represents two problems. First, there is an uncertainty about the reason for the missing responses. Was this a demonstration of design problems with the questionnaire or was it simply an oversight by the respondent? Secondly, missing data has an impact on scoring procedures and the ability to interpret the data. Both of these concerns will be addressed including strategies for the management of the missing data.

In total, there were 13 missing responses from items (10) or questions (3) among four subjects. In other words, 98.8% of the responses for the demographic questions were usable and 98.5% of responses for scale items were usable. As shown in Table 4.1 question #4 was unanswered by each of three subjects and two subjects (#1 and 8) were each responsible for five of the missing responses (77% in total).

A brief description of these two subjects follows to add context to this missing data.

Table 4.1 Missing Responses Summarized by Subject and Item or Question Number

Category	Missing Item or Question Number				Total Number of Missing Items or Questions
	Subject Number (n=17)				
	1	5	6	8	
Prejudice					
Stigma socialization				25	1
Discrimination	34, 35, 40	35			4
Coping mechanisms	44			43, 44, 45, 46	5
Demographics	4	4	4		3
Total	5	2	1	5	13

4.5.2.2.a Descriptive Analysis

4.5.2.2.a i) Subject Number One

Subject #1 had a high level of energy and was very talkative. He described how changes in medication had affected his life. He commented on how he had felt on a variety of drugs and the different side effects he had experienced. He described encounters with the law where he was hand-cuffed. He held a strong level of distrust in authority figures yet he was very generous in sharing information. He had brought clippings from newsletters about medications to share with the investigator.

On a few occasions, he added comments on the questionnaire to qualify answers. One in particular was very poignant. It was concerning item #31 which stated *"I have*

been avoided by others because I have a mental illness". He responded "sometimes" but added that it "works both ways – friends [can] seem compassionate and more caring".

He missed four items and one question in the survey. Two of these items were located at the bottom of a page (#34 and 35); it is suspected that missing these items was an oversight. The third item (#40) was treated as a missing item because he had changed the content of the question to read "criminal disputes". The last item he missed (#44) was about whether he had ever claimed to have a different diagnosis to avoid rejection. He shaded the outer edge of both boxes for the choices never and always. This response was also treated as a missing item. Lastly, he omitted answering question #4, which referred to the duration of the illness. This question was also problematic for three other subjects.

4.5.2.2.a ii) Subject Number Eight

Subject #8 presented a much different view on socialization and experience with mental illness than the others. This subject did not respond to four of the five items regarding coping skills and responded "does not apply" to 13 of the 16 items regarding discrimination. The subject explained that after "coming down with mental illness I left my family and friends", indicating that she did not give her family or friends an opportunity to react to her mental illness either supportively or not. By the time her mental illness fully developed her formal schooling was complete, and therefore never encountered situations of applying for admission to education programs or having teachers or instructors know about her mental illness.

The subject emphasized that her social network was predominantly comprised of other people with a mental illness, or people who cared for the mentally ill. Consequently, issues of being avoided because she had a mental illness and most of the coping mechanisms she felt did not apply. The subject wrote, "I have been personally spoiled. Because of my illness, my nurses, etc. have helped me recover to the fullest capacity I can be." She stated that she was set up with an approved home, and works as a volunteer. This subject did not encounter many of the situations presented.

4.5.2.2.b Questionnaire Design

The two descriptions of the subjects who predominantly were responsible for the missing responses illustrated that the rationale for the non-responses were a combination of questionnaire design and an oversight. A change in question number four and the addition of another question are expected to decrease the prevalence of missing responses in the future.

A response for question number four was omitted on three occasions and resulted in one participant request the information from her medical files. In turn, this question was considered too demanding. It will be revised in the next draft of the questionnaire. The original question asked, *"What year did you start receiving this care?"* The revised question will ask *"How long have you received care for your mental illness?"* The following response options will be provided: *"less than 1 year, 1-5 years, 6-10 years, and more than 10 years"*.

Subject #8 predominantly interacted with others who had a mental illness or mental

health care providers. In turn, this precluded her from many situations found to be rejecting by others. Consequently, her responses for a number of items about discrimination and coping mechanisms were left unanswered. The addition of a question asking the respondents to categorize the interactions will help qualify missing items in these two subscales and add to the description of the respondents. The new question would be *"Who do you mainly interact with?"* Response options would be: *"other people with a mental illness or mental health care workers, or people who do not have a mental illness or work in mental health care, or equal halves of the previous two choices."*

4.5.3 Frequency Distributions

The distribution of responses was determined for each item and question, and was summarized within each of the following categories or subscales: demographic, prejudice, stigma socialization, discrimination, and coping mechanisms. Items were reviewed individually for variability and skew to assess their potential to discriminate among individuals. Items lacking variability or were highly skewed would be considered problematic. A relatively high item variance and an item mean close to the centre of the range of possible answers are both desirable attributes for a scale (DeVellis, 1991). Item variance is a measure diversity of responses within an item. To take an extreme case, if all individuals answer a given item identically, the item will not discriminate at all among individuals with different levels of the construct being measured, and its variance would be zero. In contrast, if responses are diverse, then eventually the range of scores for an item

should be diverse as well. This implies a fairly high variance. Item means describe the central tendency of responses. Generally, items with means too near to an extreme of the response range will have low variances, which is undesirable.

4.5.3.1 Demographic Information

Results from the questions regarding demographics are summarized in Tables 4.2 and 4.3. The subjects were 53% female and 47% male within the ages of 23 and 51 years. The mean age was 34.6 with a standard deviation of 7.5 years.

Consistent with the study inclusion criteria, all subjects had received care for a mental health problem from a psychiatrist, a family doctor, or a professional at a mental health clinic. The participants had four to 22 years of treatment for their mental illness; however, there were three missing responses for this question. The mean duration of treatment was 12.0 years with a standard deviation of 6.3 years.

All subjects had been admitted to hospital to receive treatment for their mental illness. Each had stayed in the psychiatric ward in a general hospital. Some subjects (41%) also stayed in a psychiatric institution (mental hospital) while others (12%) also stayed in a non-psychiatric ward in a general hospital. Sixty-five percent of the individuals had been formally committed to hospital.

The majority of subjects (76%) were never married. Three (18%) were divorced and one (6%) was with a partner (but not married). Most subjects lived with roommates (47%) or alone (29%). The remaining lived either with their parents or siblings (18%) or with a spouse or partner (6%).

Most subjects lived in a rented home (41%) or in supported housing (29%). Two subjects (12%) lived in someone else's home rent-free, while two others (12%) lived in someone else's home but paid for room and board. Only one person (6%) lived in a group home.

The highest level of education achieved was distributed over the six categories: less than high school - 35%; high school graduate - 6%; studies after high school having not received a degree or diploma - 24%; college diploma - 6%; university degree - 18%; and university studies after receiving one university degree - 12%.

Thirty-five percent of the subjects were currently employed part-time or casually. They each had worked regularly for the past three months. Most of the subjects (71%) were involved in volunteer activities. Twenty-nine percent were students, while one, or six percent of the participants was a homemaker. Three subjects (18%) indicated that they were unable to work because of their mental health problems, while one subject (6%) was unable to work because of a physical injury or disability. Two subjects (12%) were unemployed and looking for work. One subject was retired (6%).

Table 4.2: Summary of Pilot Test Results for Demographic Questions 1-7, 47, and 48

Demographics: Question	Responses (%) (n=17)
1. Gender:	
• male	8 (47)
• female	9 (53)
2. Age:	Range 23 - 51 Mean 34.6 ± 7.5
3. Received care for mental health problem:	
• yes	17 (100)
• no	-
4. Number of years since the beginning of mental health care.	Range 4 - 22 Mean 12.0 ± 6.3 (n=13)
5. Admitted to hospital to receive treatment for a mental illness	
• yes	17 (100)
• no	-
6. Stayed in a: (Checked as many as applied.)	
• psychiatric institution (Mental hospital)	7 (41)
• psychiatric ward in a general hospital	17 (100)
• non-psychiatric ward in a general hospital	2 (12)
• other: ICU, rehab. centre	2 (12)
7. Formal commitment:	
• yes	11 (65)
• no	6 (35)
47. Marital status:	
• single (never married)	13 (76)
• with a partner (but not married)	1 (6)
• married	-
• separated	-
• divorced	3 (18)
• widowed	-
48. Living arrangement:	
• alone	5 (29)
• with your spouse or partner	1 (6)
• with parents or siblings	3 (18)
• other: roommates	8 (47)

Table 4.3: Summary of Pilot Test Results for Demographic Questions 49-54

Demographics: Question	Responses (%) (n=17)
49. Housing arrangement:	
• your own home	-
• a rented home	7 (41)
• in someone else's home rent free	2 (12)
• supported housing	5 (29)
• group home	1 (6)
• homeless shelter	-
• other: *room & board*	2 (12)
50. Highest level of education	
• less then high school	6 (35)
• high school graduate	1 (6)
• studies after high school (no degree or diploma)	4 (24)
• college diploma	1 (6)
• university degree	3 (18)
• university studies after receiving one university degree	2 (12)
51. Currently employed:	
• yes	6 (35)
• no	11 (65)
52. Employment:	
• full-time	-
• part-time or casual	6 (35)
53. Worked regularly for the past 3 months:	
• yes	6 (35)
• no	-
54: Other activities:	
• self-employed	-
• a homemaker	1 (6)
• a student	5 (29)
• a volunteer	12 (71)
• retired	1 (6)
• unable to work because of my mental health problems	3 (18)
• unable to work because of another illness	-
• unable to work because of physical injury or disability	1 (6)
• unemployed and looking for work	2 (12)

4.5.3.2 Prejudice

Table 4.4 summarizes the response distribution for items regarding prejudice. The responses demonstrated good variability being distributed over two of the four response options for seven percent of the items, and over three of the response options for 50% of the items. Six items had responses in each of the four choices (43%). The answers were predominantly affirmative, even in the two reversed items (#10, and 17). The distribution of responses among the four options were divided as follows: "strongly agree" - 31%; "somewhat agree" - 49%; "somewhat disagree" - 15%; and "strongly disagree" - 5%.

Table 4.4: Frequency Distribution for Items Regarding Prejudice

Prejudice: Item	Responses (%) (n=17)			
	SA	SWA	SWD	SD
8. I believe most people would feel afraid to talk to someone who has a mental illness	3 (18)	11 (65)	3 (18)	-
9. I think most people would be uncomfortable working with someone who has a mental illness.	6 (35)	8 (47)	2 (12)	1 (6)
10. I believe most people would stay friends with someone who has a mental illness, once they found out about the mental illness. (R)	3 (18)	8 (47)	6 (35)	-
11. I think most people would feel uncomfortable living with someone who has a mental illness.	2 (12)	13 (76)	-	2 (12)
12. I think most people would not date someone who has a mental illness.	6 (35)	8 (47)	3 (18)	-
13. I believe most people would not marry someone who has a mental illness.	5 (29)	11 (65)	-	1 (6)
14. I think most people believe that entering a hospital for psychiatric care would be a sign of personal failure.	4 (24)	8 (47)	3 (18)	2 (12)
15. I think most people would feel ashamed if others knew that someone in their family has a mental illness.	4 (23)	6 (35)	4 (23)	3 (18)
16. I think most people would be against having a group home in their neighbourhood for people who have a mental illness.	3 (18)	11 (65)	2 (12)	1 (6)
17. I think most people would believe that a person who has a mental illness could be intelligent. (R)	3 (18)	7 (41)	6 (35)	1 (6)
18. I believe most people would ignore the opinions of someone who has a mental illness.	5 (29)	8 (47)	4 (24)	-
19. I think most employers would pass over the application of someone who has a mental illness in favour of another applicant.	11 (65)	6 (35)	-	-
20. I believe most people would not hire someone who has a mental illness to take care of a family member (e.g., child, elderly parent).	13 (76)	3 (18)	1 (6)	-
21. I believe most people think that a person who has a mental illness is likely to harm others.	6 (35)	7 (47)	2 (12)	1 (6)
Total	74 (31)	116 (49)	36 (15)	12 (5)

SA = strongly agree; SWA = somewhat agree; SWD = somewhat disagree; SD = strongly disagree; (R) = reversed item

4.5.3.3 Stigma Socialization

Table 4.5 summarizes the response distribution for items regarding stigma socialization. The responses were well distributed over three of the four response options for 25% of the items, and over each of the four response options for 75% of the items. The predominant answer was "sometimes" which chosen 37% of the time. "Never" was the second most common answer selected (24%) followed by "rarely" (21%). "Often" was chosen 18% of the time.

Table 4.5: Frequency Distribution for Items Regarding Stigma Socialization

Stigma Socialization: Item	**Responses (%) (n=17)**			
	N	**R**	**S**	**O**
22. Within the last 4 months, I have seen hurtful or offensive news stories on TV or in the newspaper about people who have a mental illness.	2 (12)	4 (23)	6 (35)	5 (29)
23. Within the last 4 months, I have heard people say offensive things about people who have a mental illness.	2 (12)	4 (24)	9 (53)	2 (12)
24. I have been told by a health care professional to hide my mental illness to avoid rejection.	9 (53)	3 (18)	5 (29)	-
25. I have been told by health care professionals to lower my personal goals because I have a mental illness. * (n=16)	3 (19)	3 (19)	5 (31)	5 (31)
Total	16 (24)	14 (21)	25 (37)	12 (18)

N = never; R = rarely; S = sometimes; O = often; * = missing item(s)

4.5.3.4 Discrimination

The frequency distribution for the portion of the scale addressing discrimination is shown in Table 4.6. There were four missing items in this section of the questionnaire. In this section, the respondents were asked to respond "does not apply" if they were never in the described situation. This response was chosen on 58 occasions (22%) for the seventeen subjects. The two items that contributed the most to the "does not apply" responses were #39 (14%) and item #40 (17%). The former stated "*I have been treated fairly by law enforcement officers when I told them I have a mental illness*" and the latter stated *"My diagnosis of mental illness was used against me in non-criminal disputes (e.g., child custody or divorce proceedings)*." Only two of the sixteen situations described (items #37 and 38) were applicable to each subject. This represents a large variability between subjects. Implications for scoring will follow.

The distribution of responses, for the situations that were applicable to the subjects, was as follows: "never" – 18%; "rarely" – 9%; "sometimes" – 24%; "often" – 13%, and "always" – 14%. In four of the 16 items (31%) responses were distributed over each of the five options offered. While in six items (38%) responses were distributed over four of the five options offered. Four items (25%) had responses spread over three choices. The responses for the remaining item (6%) were limited to two of the five options. This last item (#36) related to renting a home.

Table 4.6: Frequency Distribution for Items Regarding Discrimination

Discrimination: Item	Responses (%) (n=17)					
	N	R	S	O	A	DNA
26. Family members who know I have a mental illness have been supportive. (R)	-	1 (6)	3 (18)	5 (29)	6 (35)	2 (12)
27. Friends who know I have a mental illness have been supportive. (R)	-	-	7 (41)	6 (35)	3 (18)	1 (6)
28. I did not get accepted into a school or an education program because I have a mental illness.	10 (59)	-	2 (12)	1 (6)	-	4 (24)
29. Teachers or instructors who know I have a mental illness have been supportive. (R)	1 (6)	1 (6)	2 (12)	4 (24)	3 (18)	6 (35)
30. Once others knew I have a mental illness I was treated as less able to do a job.	3 (18)	1 (6)	9 (53)	2 (12)	1 (6)	1 (6)
31. I have been avoided by others because I have a mental illness.	2 (12)	4 (24)	9 (53)	1 (6)	-	1 (6)
32. I have been excluded from volunteer activities because I have a mental illness.	5 (29)	5 (29)	3 (18)	2 (12)	-	2 (12)
33. Supervisors at work were supportive when I told them I have a mental illness. (R)	2 (12)	2 (12)	1 (6)	3 (18)	3 (18)	6 (35)
34. I have lied on applications (for work, housing, etc.) that asked if I had a mental illness for fear that the information would be used against me. * (n=16)	5 (31)	5 (31)	3 (19)	-	2 (13)	1 (6)

Table 4.6: Frequency Distribution for Items Regarding Discrimination Continued

Discrimination: Item	Responses (%) (n=17)					
	N	R	S	O	A	DNA
35. I have been turned down for employment for which I was qualified when I disclosed I have a mental illness. * (n=15)	6 (40)	2 (13)	3 (20)	-	-	4 (27)
36. I have had difficulty renting a home because I have a mental illness.	9 (53)	-	2 (12)	-	-	6 (35)
37. General health care providers have been supportive when I told them I have a mental illness. (R)	-	-	7 (41)	3 (18)	7 (41)	1 (6)
38. I have been treated fairly by the nurses and doctors when I used hospital emergency service for my mental illness. (R)	1 (6)	2 (12)	4 (24)	4 (24)	6 (35)	-
39. I have been treated fairly by law enforcement officers when I told them I have a mental illness. (R)	1 (6)	-	5 (29)	1 (6)	2 (12)	8 (47)
40. My diagnosis of mental illness was used against me in non-criminal disputes (e.g., child custody or divorce proceeding). * (n=16)	1 (6)	1 (6)	2 (13)	-	2 (13)	10 (63)
41. Leaders within my religious community have been supportive when I told them I have a mental illness. (R)	1 (6)	1 (6)	3 (18)	4 (24)	2 (12)	6 (35)
Total	47 (18)	25 (9)	65 (24)	36 (13)	37 (14)	58 (22)

N= never; R= rarely; S= sometimes; O= often; A= always; DNA= does not apply; (R)= reversed item; * missing item(s)

4.5.3.5 Coping Mechanisms

As shown in Table 4.7, the distribution of responses for the five items regarding coping mechanisms were generally focused on the "sometimes" option (48%). The second most common response was "always" (21%); followed by "often" (13%). The options that were selected least often were "rarely" (11%) and "never" (8%).

Of the five items, three of the responses were distributed over four choices. One item (#45) had responses spread over each of the options offered. The final item had choices selected over three of the possibilities.

The prominence of the "sometimes" response was thought to reflect the tendency to choose the neutral response in a five-point scale. This central tendency results in a loss of sensitivity and reliability. This subscale was revised to four-points to force the respondents to commit themselves to one side or the other. The adjectives were changed to "rarely", "seldom", "usually", and "often" in draft four of the questionnaire.

Table 4.7: Frequency Distribution of Items Regarding Coping Mechanisms

Coping Mechanisms: Item	Responses (%) (n=17)				
	N	R	S	O	A
42. I keep my diagnosis of mental a secret to avoid rejection.	-	1 (6)	10 (59)	3 (18)	3 (18)
43. When I am with others I try to hide any visible signs of my mental illness. * (n=16)	-	3 (19)	6 (38)	2 (13)	5 (31)
44. I have claimed to have a different diagnosis to avoid rejection. * (n=15)	5 (33)	3 (20)	7 (47)	-	-
45. I try to explain my illness to others to help them understand. * (n=16)	1 (6)	1 (6)	7 (44)	1 (6)	6 (38)
46. I avoid people who have made negative comments about people with a mental illness. * (n=16)	-	1 (6)	8 (50)	4 (25)	3 (19)
Total	6 (8)	9 (11)	38 (48)	10 (13)	17 (21)

N = never; R = rarely; S = sometimes; O = often; A = always; * missing item(s)

4.5.3.6 Overall Distribution of Response Options

Table 4.8 summarizes the distribution of total number of response categories selected per item (as a percentage) for each category or subscale. It shows that in items that offer four response options over 90% of the items had responses distributed over three or four of the choices. When five response options were provided, 69% or more of the items had a spread of responses over the four to five choices. Based on this summary and the frequency distributions for individual items the responses were considered well distributed for items regarding prejudice, stigma socialization, and discrimination. The responses for items regarding coping mechanisms were not as well distributed.

Table 4.8: Distribution of Total Number of Response Categories Selected Per Item (as a percentage) for Each Theme Category or Subscale

Category or Subscale	Total Number of Response Categories Selected Per Item as Percent				
	1	2	3	4	5
Prejudice	-	7	50	43	X
Stigma socialization	-	-	25	75	X
Discrimination	-	6	25	38	31
Coping mechanisms	-	-	20	60	20

X= not applicable

4.5.4 Clarity Check

After completing the questionnaire, each subject was asked the following five questions (identified during the evaluation of clarity by Masters Students), regarding the intent of certain words used in the questionnaire. Their comments are summarized after each question.

1) Whether being hospitalized "against your will or involuntary" was interpreted as being committed under the Mental Health Act (question #7)? All subjects, except one understood the intent of the question. Nevertheless, one subject suggested including "under the Mental Health Act" in parenthesis. This question was revised as suggested.
2) Who was included in the group of "most people" when they assessed whether "most people would feel uncomfortable living with someone who has a mental

illness" (item #11)? When subjects were formulating their responses three groupings were identified. Some subjects grouped all those people they knew and evaluated them as to whether they would be uncomfortable living with someone who has a mental illness. One subject specified grouping all non-family members. The third grouping was the public. This item remained intact.

3) Who was included in the grouping of "general health care providers" (item #37)? All except one subject regarded "general health care providers" to include psychiatrists; most also included psychologists, general practitioners, nurses and associated support staff within and outside the mental health services field. This item was revised to exclude mental health care providers.
4) Whether the word "fairly" adequately covers the feelings of being treated courteously, respectfully, as a person by the nurses and doctors in emergency services (item #38), or by law enforcement officers (item #39). Generally, all subjects agreed that the word "fairly" was a good choice, but that "courteous and polite" could be included in parenthesis. These two items were left intact.
5) What the respondent tries to hide, if they were to "hide any visible signs" of their mental illness (item #43). Responses ranged considerably for this item. In some cases, the subject was "hiding" through total withdrawal or by not sharing their opinions. Another subject interpreted this phrase as concealing pill taking. One used the following example: He stated that if he lost track of a conversation because he heard voices (hallucination) he would ask to have

that part of the conversation repeated without explaining what had happened. The item was left intact.

The observations made about issues of ambiguity came from requests for clarification by the subjects and by notations made on the completed questionnaires. Additional issues were noted as errors during the preparation of the data for analysis. Comments made by subjects spontaneously or in response to questions asked by the investigator helped identify and resolve other issues of ambiguity. All of these observations and the ensuing action plans for revisions have been summarized in Appendix K. For example, it was suggested, to separate parents from siblings in the item #26 since the reactions can be quite different between the two. Item #26 stated "*family members who know I have a mental illness have been supportive*". The suggested revision was made adding one more item to the scale.

4.5.5 Content Check

All the subjects were asked if they thought any topics relating to stigma and discrimination had been omitted in the questionnaire. All the comments were summarized in Appendix K. Most responded that the questionnaire appeared complete. However, one subject (#9) suggested to ask whether "you thought you would be treated the same as if you had a physical illness."

This suggestion was very similar to item #22 on the first draft of the questionnaire. It stated *"I believe most people in my community, if they knew, would treat someone who has a mental illness just as they would treat anyone."* This item was deleted from the

questionnaire because it was considered too broad or non-specific. One member of the expert panel (E25P) wondered whether "treating them the same might not be a good thing". For these reasons, this suggestion was not incorporated into the next draft of the questionnaire.

4.5.6 Scoring

To assess the impact of public education campaigns summary measures are needed that can gauge differences relating to each subscale and to the overall construct. Although it is not known if this new scale is sensitive to change, there is a method of aggregating the subscales into a summary measure that can answer the question, did this campaign lead to a reduction in felt stigma? Thus, the data were aggregated to test this procedure.

4.5.6.1 Scale Interpretation

Psychometric scaling techniques typically assume interval level data for ordinal categories if they are well distributed. Based on the earlier analysis, the responses for each subscale were well distributed except for one. Responses for items regarding coping mechanisms had a strong central tendency, which reduces the ability of the scale to distinguish change, but still permits the responses to be treated as interval data. Therefore, it was possible to assume interval level data for ordinal categories and aggregate the subscale (MacDowel & Newell, 1996; Streiner & Norman, 1995).

4.5.6.2 Scoring Procedure

The scoring approach chosen is conceptually and arithmetically simple, and makes few assumptions about the individual items. The only implicit assumption is that the items are equally important in contributing to the overall score.

All items were scored so that a high score indicated a belief that a person with a mental illness was devalued and discriminated against. Adding the individual item scores from each subscale (prejudice, stigma socialization, and coping mechanisms) resulted in the overall measure of stigma.

4.5.6.3.a Missing Items

When calculating scores from items that have missing responses the researcher is faced with four options. The researcher can (a) ignore the missing data, (b) omit persons with missing data from the study (c) omit the persons from the particular analysis of a subscale that contains the missing data, or (d) find a way to replace the missing data with an estimate of what the missing item might be.

Ignoring the missing items and summing over the remaining items leads to an underestimation of the individual's score. Dropping the participants with missing data from the analyses could reduce the power and accuracy of the analyses, particularly where missing data are extensive. Substituting a neutral value (e.g., the mean of all of a given person's completed items for those items that the person has not completed) has been found to result in a good representation of the original data when the number of items missing were 20% or less. This replacement method is called the person mean substitution

approach and it is applied to preserve data (Downey & King, 1998).

Based on this evidence items were analyzed in each category (subscale) if 80% or more of the items were completed by a subject. A person mean substitution approach was used for missing items in scoring subscales when the number of items missing per subject was less than 20%. If more than 20% of the items in a category or subscale for a subject were missing, the analysis of that subscale would be omitted for that individual.

The maximum number of missing items permitted in each subscale was calculated and shown in Table 4.9.

Table 4.9: Maximum Number of Missing Items in Each Theme Category or Subscale Based on a 20% Limit

Category or Subscale	Number of Items	Maximum Number of Missing Items Permitted
Prejudice	14	2
Stigma socialization	4	0
Discrimination	16	3
Coping mechanisms	5	1

Only one subject (#8) exceeded the maximum limit for missing items in two subscales. This subject was omitted from further analysis because of the missing responses. Although subject #1 had an equal number of missing responses, the maximum limit for missing items in a subscale was not exceeded. This subject was included in the following analysis using the mean substitution approach.

4.5.6.2.b Discrimination

Items regarding discrimination were not suited for scoring because the variability between the number of situations a subject was able to respond to was too great to make a meaningful comparison. A scale assumes all subjects have had uniform exposures to the situation. This was not the case with respect to the discrimination subscale. Consequently, data from items regarding discrimination can only be used descriptively through frequencies.

4.5.6.3 Results

The individual scores for each theme category or subscale are summarized in Table 4.10. The range of scores and mean with standard deviation for each theme category or subscale was determined and summarized in Table 4.11. Box plots were used to illustrate the centre, and spread in the data. A scale that has scores well distributed without a strong skew are more capable of detecting change. Figures 4.1, 4.2, 4.3, and 4.4 respectively, are box plots of the scores of the subscale prejudice, stigma socialization, and coping mechanisms and the overall measure of stigma.

Table 4.10: Individual Scores for Each Theme Category or Subscale

Theme Category or Subscale	Subject Number (n=16) (%)															
	1	**2**	**3**	**4**	**5**	**6**	**7**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**17**
Prejudice Items #8 – 21 Maximum score = 56	54	38	42	44	46	38	43	41	45	48	37	38	46	44	27	30
Stigma socialization Items #22 – 25 Maximum score = 16	12	12	6	14	10	11	11	11	10	11	10	9	7	10	14	6
Coping mechanisms Items #42 – 46 Maximum score = 25	20	16	23	19	20	13	14	15	19	16	16	15	17	13	14	12
Overall Stigma Score Maximum score = 97	86 (89)	66 (68)	71 (73)	77 (79)	76 (78)	62 (64)	68 (70)	67 (69)	74 (76)	75 (77)	63 (65)	62 (64)	70 (72)	67 (69)	55 (57)	48 (49)

Table 4.11: Score Range and Mean with Standard Deviation for Each Theme Category or Subscale

Theme Category or Subscale	Number of Items	Maximum Possible Score	Range	Mean ± Standard Deviation
Prejudice	14	56	27 – 54	41.3 ± 6.7
Stigma socialization	4	16	6 – 14	10.3 ± 2.4
Coping mechanisms	5	25	12 – 23	16.4 ± 3.1
Overall Stigma Score	23	97	48 – 86	67.9 ± 9.1

4.5.6.3.a Prejudice

The subscale prejudice consisted of 14 items each offering a choice of the following responses: strongly agree, somewhat agree, somewhat disagree, and strongly disagree. A high score for an item was four, and a low score was one.

Scores for the subscale prejudice ranged from 27 to 54 out of a possible maximum score of 56. The mean score was 41.3 with a standard deviation of 6.7. Dividing the mean by the number of items in the subscale translates to a score 3.0 which approximates the response "somewhat agrees". This result would indicate that the on average individuals in the sample believed that a person with a mental illness was devalued.

As illustrated in Figure 4.1, scores regarding prejudice were well distributed over the middle 50% of the data with no outliers or extreme values.

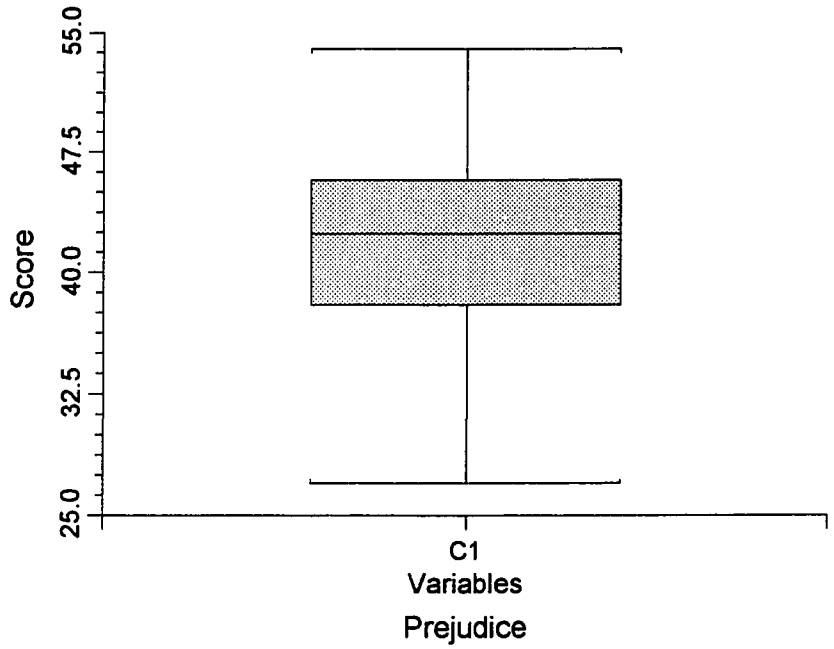

Figure 4.1: Box Plot for Scores of Items Regarding Prejudice

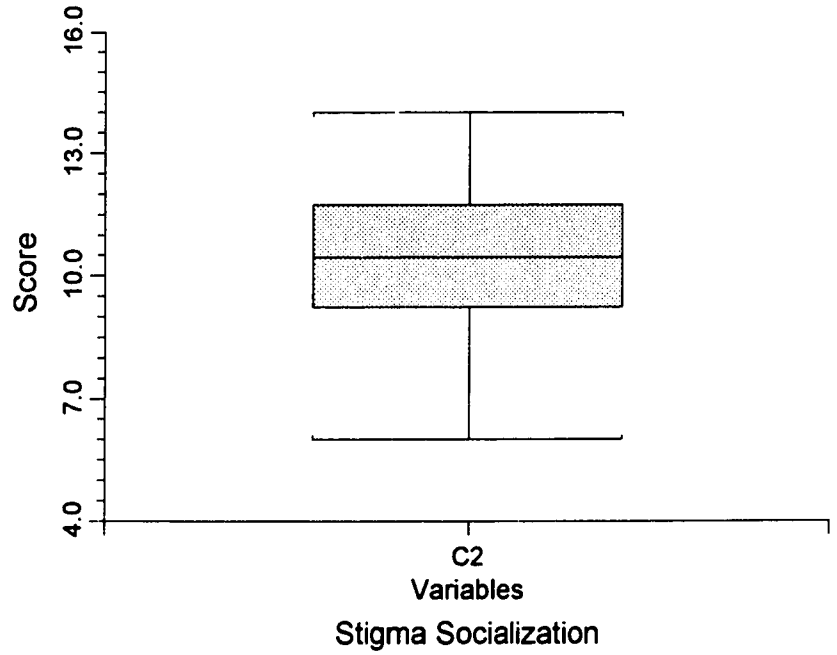

Figure 4.2: Box Plot for Scores of Items Regarding Stigma Socialization

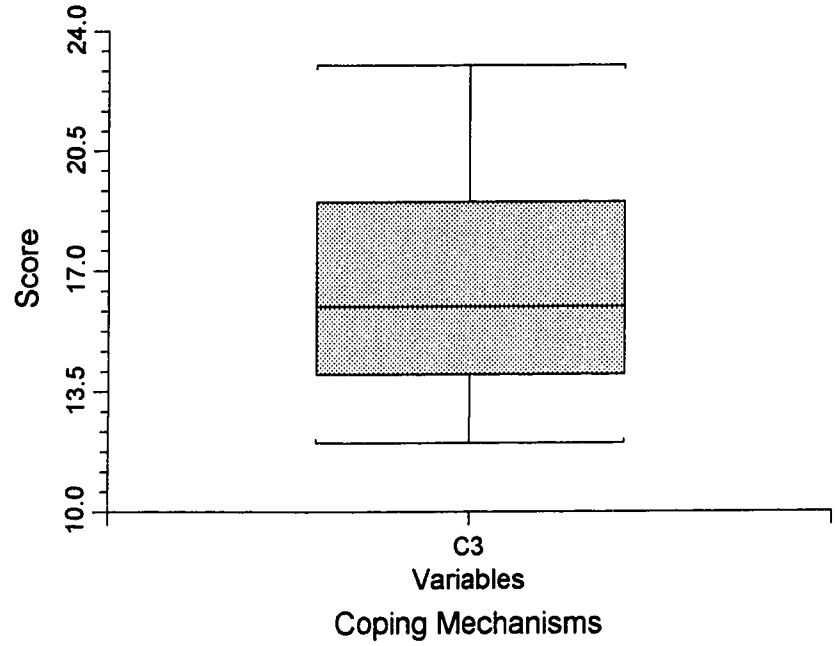

Figure 4.3: Box Plot for Scores of Items Regarding Coping Mechanisms

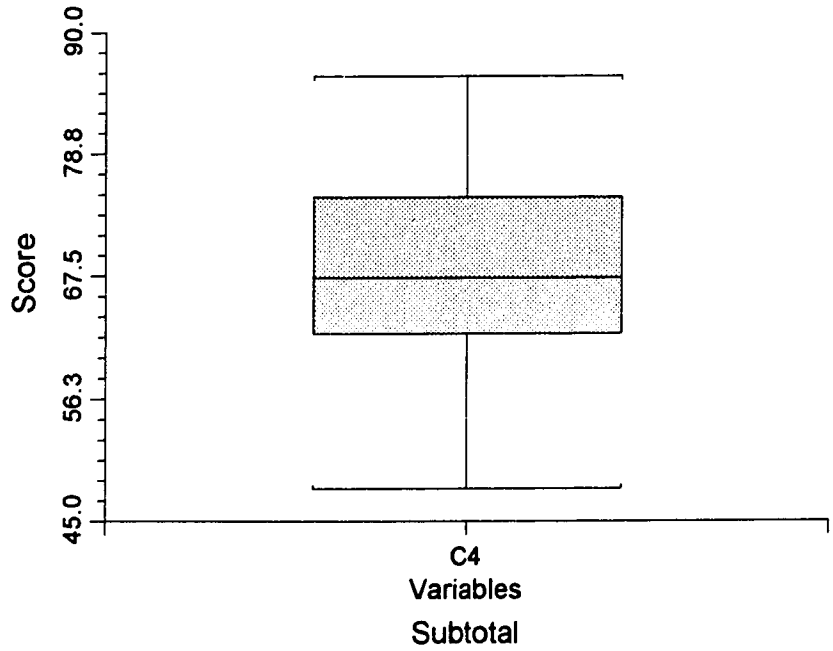

Figure 4.4: Box Plot for Overall Stigma Scores (Aggregate of Scores for Prejudice, Stigma Socialization, and Coping Mechanisms)

4.5.6.3.b Stigma Socialization

The subscale stigma socialization consisted of four items each offering a choice of the following responses: often, sometimes, rarely, and never. A high score for an item was four, and a low score was one.

Scores for the subscale stigma socialization ranged from six to 14 out of a possible maximum score of 16. The mean score was 10.3 with a standard deviation of 2.4. Dividing the mean by the number of items in the subscale translates to a score 2.6, which approximates a response between "sometimes" and "rarely". This result would indicate that the on average individuals in the sample believed they were negatively socialized about their mental illness between the frequencies "rarely" and "sometimes".

As illustrated in Figure 4.2, scores regarding stigma socialization were well distributed over the middle 50% of the data with no outliers.

4.5.6.3.c Coping Mechanisms

The subscale regarding coping mechanisms consisted of five items each offering a choice of the following responses: always, often, sometimes, rarely, and never. Depending on the direction of the statement a high score for an item was five, and a low score was one.

Scores for this subscale ranged from 12 to 23 out of a possible maximum score of 25. The mean score was 16.4 with a standard deviation of 3.1. Dividing the mean by the number of items in the subscale translates to a score 3.3, which approximates the response

"sometimes". This result would indicate that the on average individuals in the sample sometimes used the coping strategies like secrecy, withdrawal, and education.

As illustrated in Figure 4.3, scores regarding coping mechanisms were well distributed over the middle 50% of the data with no outliers or extreme values.

4.5.6.3.d Overall Stigma Score

The overall stigma score was an aggregate of the scores from each of the subscales prejudice, stigma socialization, and coping mechanisms. The overall score ranged from 48 to 86 out of a possible maximum score of 97. The mean score was 67.9 with a standard deviation of 9.1.

Because the numbers of options were uneven between the three subscales, a translation by dividing by the number of total items is not feasible. Alternatively, the overall score for stigma can be represented as the raw score or a percentage. As a percentage, the average score would be 70%.

Figure 4.4 illustrates the distribution of the overall score in a box plot. As with the previous scales, the spread is well distributed with no outliers or extreme values.

4.6 Questionnaire Refinement

4.6.1 Scale Items and Questions

Based on the results of the pilot test the questionnaire was refined once more. As shown in Table 4.12 five items and eight demographic questions were revised, a total of 13 or 24% of third draft of the questionnaire. Two additions were made to the

scale. The first addition was created when item #26 was split to separate support of parents from those of brother(s) or sister(s). The new item states "*My brother(s) and sister(s), who know I have a mental illness, have been supportive*". The second addition was a question designed to aid in the interpretation of missing responses, or extreme results. This question asked the respondent to categorize their interactions into one of three categories.

Table 4.12: Number of Item or Question Revisions, and Additions Resulting from the Pilot Test

Category	Number of Items or Questions				
	Draft 3				Draft 4
	Original	Revised	Unchanged	Added	
Prejudice	14		14		14
Stigma socialization	4	2	2		4
Discrimination	16	3	13	1	17
Coping mechanisms	5		5		5
Demographics	15	8	7	1	16
Total	54	13	41	2	56

4.6.2 Format

The format of the questionnaire appeared to work well with one exception. While cleaning the data it became apparent that with a series of related demographic questions (e.g., #51-53, and 3, 6, and 7), it was better to compensate for too many questions answered than too few. Consequently, the emphasis on skip patterns will be lessened to include only the directional box, such as **IF NO, GO TO QUESTION 54.** and to delete the use of arrows.

4.6.3 Draft Four of the Questionnaire

The fourth draft of the questionnaire had a total of 50 items and 16 questions: prejudice – 14; stigma socialization – 4; discrimination – 17; coping mechanisms – 5; and demographics - 16. See Appendix L for the revised questionnaire. This is the version that will now undergo further testing in a subsequent study.

The proposed study will involve the administration of the questionnaire to a large representative sample of consumers. Three objectives have been identified to evaluate the validity and reliability of the stigma scale. First, to identify and resolve unexpected problems in administration which have not become known in the pilot testing phase. Second, to evaluate whether the scale items measure what they purport to measure and do so efficiently. Thirdly, to develop preliminary estimates of population norms for felt stigma among psychiatric patients seeking acute treatment.

CHAPTER FIVE: DISCUSSION

5.1 Introduction

The aims of this study were to develop a self-report questionnaire designed to assess stigma and discrimination because of schizophrenia, and then to assess the content validity and procedural feasibility of this questionnaire among selected individuals diagnosed and receiving treatment for schizophrenia. The objectives of this final chapter are to (a) summarize the major findings, (b) discuss some of the practical implications of the results, (c) address the strengths and limitations of the study, and (d) suggest areas for further study.

5.2 Summary of Major Findings

5.2.1 Literature Review

Stigma is socially and culturally defined and reflects society's response to individuals who possess some undesirable deviation form the norm. Society's response may be expressed as mild intolerance or, as in the case of mental illness, in ways that are more deeply discrediting, including socially prejudicial and discriminatory practices (Goffman, 1963; Jones et al., 1984). While legislation exists to prevent such discrimination, social barriers are erected to keep the stigmatized at a comfortable social distance (Albrecht et al., 1982).

Although stigma has been measured in terms of public expressions of intolerance and social distance, scales adopting a consumer-perspective do not currently exist

(Cumming & Cumming, 1957; Albrecht et al., 1982; Angermeyer & Matschinger, 1995). Consequently, it is impossible to evaluate the effects of anti-stigma programs directly; that is the extent to which they improve the circumstances of the mentally ill.

5.2.2 Instrument Development

Relevant theoretical, empirical, and qualitative literature was reviewed for constructs and themes that could be related to felt stigma either theoretically or experientially. An effort was made to include qualitative reports depicting the phenomenology of mental illness to ground the development of the questionnaire in experiential data. Scale items were developed to elicit information about each theme. When available items were adapted from existing instruments measuring related constructs. These items were augmented with original items. The scale was developed to take the form of a paper-and-pencil questionnaire that was brief, easy for chronically ill populations to complete.

With the addition of a small number of items or questions, the content of the questionnaire was considered comprehensive by a panel of experts. Improvements to the clarity of the scale items and demographic questions were made with each revision of the questionnaire. Checks for clarity began with the expert panel and subsequently by fellow students in the Masters Program in the Department of Community Health Sciences. Words or phrases were simplified, made more direct or revised to be more familiar to the target population. In a few questions response categories were modified to accept multiple responses or redefined to ensure the categories were mutually exclusive.

5.2.3 The Pilot Test

5.2.3.1 The Study Sample

The third draft of the questionnaire was tested among a small number of consumer volunteers who had been clinically diagnosed with schizophrenia, had a broad range of functional abilities, and were either attending a day hospital program or were members of a local consumer association. These individuals were chosen because they are among those at highest risk of experiencing psychiatric stigma and among those who would have the most difficulty completing questionnaires.

5.2.3.2 Evaluation of Content and Validity

Subjects assessed the content of questionnaire as comprehensive. Based on the comments of the subjects and their responses to the items and questions the questionnaire was revised once more to improve clarity. A particularly troublesome question that required the subjects to recall the year they started treatment was modified to permit greater approximations.

5.2.3.3 Questionnaire Acceptability

The questionnaire was considered acceptable to the study sample because the high percent of usable data obtained. The questionnaire was suitable for all participants in the pilot test and it is thought that people with significant functional impairment (excluding active psychosis) could complete the scale. The scale is appropriate for computerization

because of its simplicity and use of standardized response scales.

5.2.3.4 Response Variability

A frequency distribution was determined for each item and question. Answers were well distributed over the response options resulting in high variability without a strong skew, with the exception of items regarding coping mechanisms. This indicates a good range of applicable choices from the design perspective and the potential to detect change from the position of interpretability. Response categories for items about coping mechanisms were modified to a four-point scale.

5.2.3.5 Scoring

A scoring procedure was used to create summary measures relating to each subscale and to the overall construct in order to assess the impact of public education campaigns. The scoring approach used was conceptually and arithmetically simple, and made few assumptions about the individual items. The only implicit assumption was that the items were equally important in contributing to the overall score. This assumption could be tested in future research using modelling approaches such as factor analysis.

5.3.3.5.a Imputing Values for Missing Data

The basic premise of imputation is that "fewer biases are introduced by estimating values for cases for which data are missing than by excluding them from the analyses altogether" (Aday, 1996, p.315). The person mean substitution approach was considered

suitable for the replacement of missing data in the subscales prejudice, and coping mechanisms (Downey & King, 1998). The premise stated above holds true for these two subscales because the value would be approximated over 12 or 13 items for the subscale prejudice and over four items for the subscale coping mechanisms. This replacement approach is not applicable to missing items in the stigma socialization subscale because there were too few items in this subscale.

5.3.3.5.a Analysis for Items Regarding Discrimination

The scoring procedure was not suited for items measuring experienced discrimination because the variability between the number of situations applicable to the subject was too large to make meaningful comparisons. Past research had assumed a homogenous level of exposure to discriminatory situations (Link, 1987; Wahl, 1998). Since not all people work, have similar friendship networks, attempt volunteer activities, and have brushes with the law, standardized scales incorporating all of these items cannot be used. Thus, a descriptive approach would appear to be most feasible for future applications. It provides a measure of prevalence (the number experiencing divided by the number at risk).

5.3 Practical Implications

The findings of this study have several implications. The growing recognition of the harmful effects of psychiatric stigma has resulted in a number of advocacy and public education efforts. This study provides a tool that with additional testing will be a reliable

and valid measure of stigma felt by consumers. Such a refined tool would be beneficial for those wishing to assess the effectiveness of these intervention efforts, or establish temporal comparisons of felt stigma over time across different population groups.

5.4 Strengths and Limitations of the Study

5.4.1 The Strengths

5.4.1.1 The Scale

The scale development followed a comprehensive strategy for design that minimizes errors. This scale relies on self-reports of individuals with schizophrenia to close-ended questions. The response to any one of the questions is subject to error: the person may misinterpret the item, or respond in a biased manner. The effect of these errors was minimized in two ways. First, each item was screened to ensure it was tapping the concept desired and the item was clear and offered appropriate responses. Secondly, the focus is on the consistency of the answers across many items, essentially disregarding the responses to the individual questions.

5.4.1.2 The Target Population

In this study, the newly designed questionnaire was tested by a sample of the target population. Therefore, the feasibility of the administration of the questionnaire and the acceptability of the questionnaire was evaluated with the audience that is being targeted.

Among the misunderstandings about schizophrenia lies a concern about the ability of persons with schizophrenia to provide reliable information. It is recognized that

schizophrenia has a course that is episodic and yields a wide variation in disability (Shepherd, Watt, Falloon, & et al. 1989). The recruitment strategy used in this study aimed at involving individuals when they were best able to reflect upon their illness. In addition, the questionnaire was designed to be simple and easy to complete for those more functionally impaired. Based on these facts, the responses provided by the subjects in this study are considered reliable.

It is also important to remember that individuals with a mental disorder are considered a vulnerable population in need of protection in the context of nontherapeutic biomedical research because of concerns about competence and voluntariness. However, while protecting the individuals their decision-making potential also needs to be respected and maximized, allowing such individuals to consent to participate in studies. Therefore, research with the mentally ill is restricted to that which furthers the understanding, prevention, or alleviation of a problem directly related to a condition or circumstance affecting the subject (Arboleda-Flórez & Weisstub, 1997). With these safeguards in place, the benefits of research would be returned to the participating group.

5.4.2 Limitations of the Study

The selection of the consumers in this study was aimed at those who were articulate, insightful, and informative. The participants' perceptions and experiences were not considered representative of the population of individuals diagnosed with schizophrenia by virtue of the sampling method and sample size.

Schizophrenia is found worldwide in all races, cultures, and social economic classes. In turn, advocacy and public education efforts to reduce the stigma of schizophrenia are being tackled globally. There are limitations in the feasibility of using this scale internationally.

Stigma is socially and culturally defined. The questionnaire developed in this study have tapped the experiences of stigma and discrimination in Canada, but likely not in other countries, particularly the developing world. Consequently, the translation of the scale and questionnaire into another language may introduce subtle forms of distortions.

5.5 Recommendations for Further Study

The full psychometric testing and validation of this instrument should be the logical next stage of research. Toward this end, a grant proposal has been prepared. The proposed study will administer the revised scale to a larger and more representative sample of consumers in order to (a) identify and resolve unexpected problems in administration which were not highlighted in the pilot investigation, (b) evaluate whether the scale items measure what they purport to measure and do so efficiently (internal consistency and construct validity), and (c) develop preliminary estimates of population norms. Subsequent studies will be needed to assess the consistency of the scale across time (test-retest reliability) and its sensitivity to change.

The ability to measure felt stigma in a standardized way might foster new areas of empirical research. The effects of felt stigma can be examined on clinical outcomes like functional ability, quality of life, or suicide. For example, a study could be conducted to

assess the relationship of felt stigma and risk of suicide. The effects of stigma on health behaviours, including treatment compliance, commitment, hospital-use, or community occupation may also be examined.

5.6 Conclusions

Measurement is a vital aspect of social and behavioural research. With careful design, assessment, and application of a measurement scale researchers are able to focus on unobservable variables to develop the clearest understanding of the relationships among such variables. The efforts of design and assessment in this study have resulted in a tool ready for more formal psychometric testing.

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WPA. WPA Programme for the Reduction of Stigma and Discrimination Because of Schizophrenia. (un pub)

Appendix A

Schizophrenia: Myths and Misunderstandings

The World Psychiatric Association's (WPA) *Global Program Against Stigma and Discrimination Because of Schizophrenia* has identified 11 popular misconceptions about schizophrenia which often significantly impact the view of the patient, and, thus, his or her treatment. All of these myths or misconceptions have been challenged by research data (WPA, 1998).

1. *Myth: Schizophrenia Is Split Personality Or Multiple Personality Disorder.*

   Fact: Schizophrenia is not multiple personality disorder, which is a hysterical or dissociative condition. Nor is it "split personality."

2. *Myth: People Never Recover From Schizophrenia*

   Fact: Schizophrenia does not invariably have a downhill course. The misconception that schizophrenia is always an incurable disease leads to hopelessness and despair, neglect, abandonment, and burnout of family members.

3. *Myth: Poor Parenting Causes Schizophrenia.*

   Fact: Psychiatrists since Sigmund Freud have regarded the family as crucial to the development of human personality and mental disorder and many have looked to the family for dynamic forces capable of creating schizophrenia. Despite this concerted effort, no evidence has been found that the family environment or poor parenting causes schizophrenia.

4. *Myth: Schizophrenia Is Contagious.*

   Fact: Schizophrenia is not contagious. However, the belief that schizophrenia is contagious is widespread around the world and is the basis for much prejudice against people with mental illness.

5. *Myth: Schizophrenia Is Caused By Evil Spirits or Witchcraft.*

   Fact: Although this is untrue in a large part of the world, many people believe that schizophrenia is caused by the action of ancestral spirits or the use of witchcraft.

6. *Myth: People with Schizophrenia Are Mentally Retarded.*

   Fact: Although, people with schizophrenia are sometimes confused with people who have mental retardation, schizophrenia and mental retardation are two very different conditions.

7. *Myth: People with Schizophrenia Have To Be Kept In the Hospital.*

   Fact: Recent studies have shown that a variety of settings, ranging from innovative alternatives to the hospital, to comprehensive community programs, can be effective in treating people with schizophrenia.

8. *Myth: Jail Is an Appropriate Place for People with Schizophrenia.*

   Fact: People with schizophrenia should not be kept in jail. People with schizophrenia are likely to get worse if treated punitively or confined unnecessarily.

9. *Myth: People With Schizophrenia Are Not Able To Make Decisions About Their Own Treatment.*

   Fact: People with schizophrenia can be involved in their treatment.

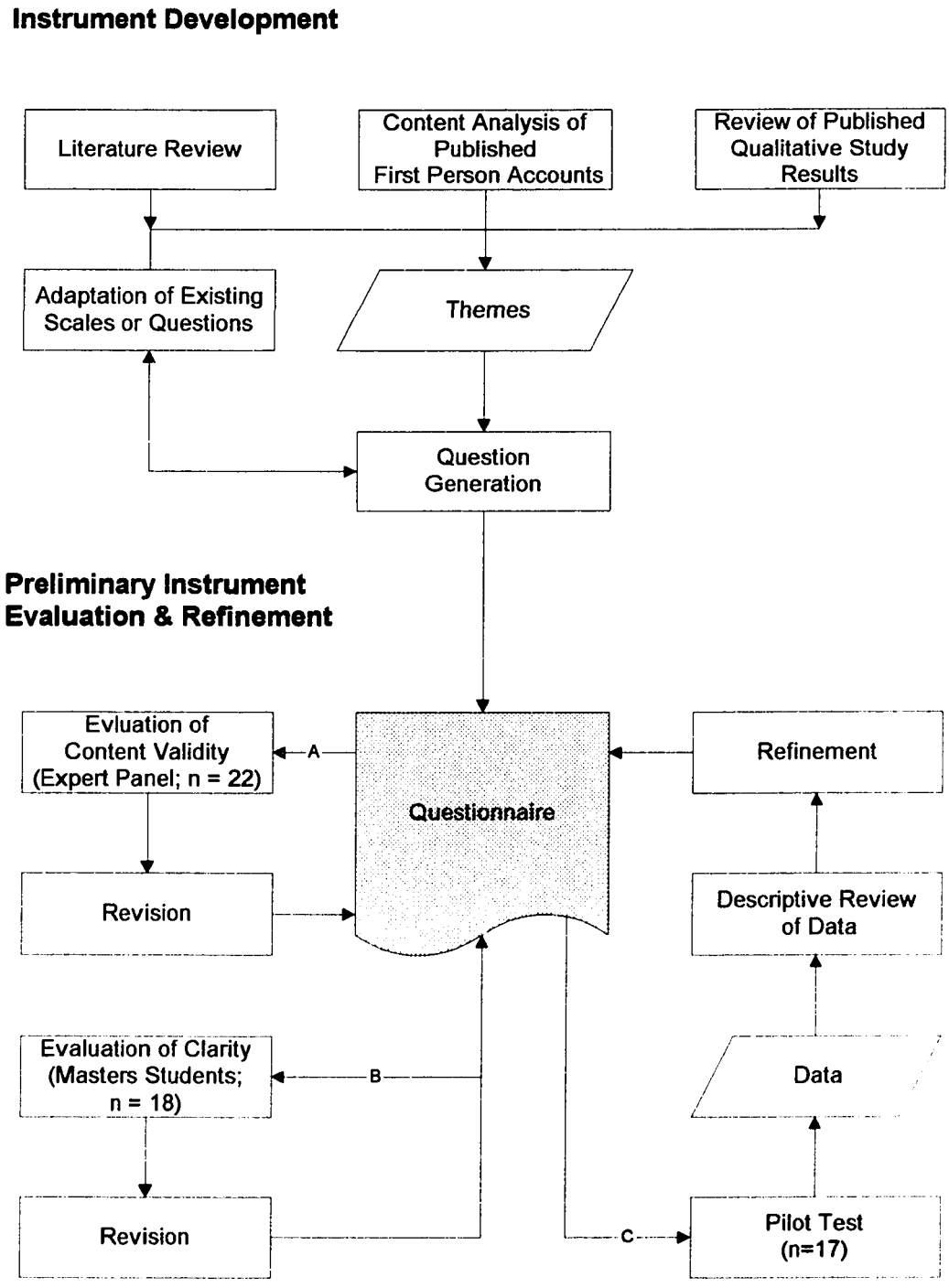
10. *Myth: People With Schizophrenia Are Likely To Be Violent.*

    Fact: People with schizophrenia are not likely to be violent.

11. *Myth: Most People with Schizophrenia Can't Work.*

    Fact: People with schizophrenia can work even if they have symptoms. Work helps people recover from schizophrenia.

Appendix B
Study Flow Chart



Appendix C

Questionnaire Draft 1

Participant No._____

We appreciate your co-operation in the development of this questionnaire. It is being devised to learn about the social effects of having a mental illness from the consumers' viewpoint. This questionnaire will undergo a number of tests to improve the questions and format. The answers and feedback you provide are valued. An investigator will be available to you while you are completing this questionnaire to assist you with any questions you may have and to receive any feedback you would like to provide. We are aware that the questions ask for personal information; be assured that your name will not be associated with your answers under any circumstances.

1. **Are you** ❒ **male** **or** ❒ **female?**

2. **What year were you born?** 19_____.

3. **What age were you when you were diagnosed with a mental illness?**
   _____ **Years**

4. **What is your current psychiatric diagnosis as defined by a doctor?**
   - ❒ Schizophrenia
   - ❒ Psychoses
   - ❒ Depression
   - ❒ Manic Depression
   - ❒ Anxiety Disorder
   - ❒ Other Please specify_____

5. **Have you ever been admitted to hospital to receive treatment for a mental illness.**
   ❒ Yes ❒ No

IF NO, GO TO QUESTION NUMBER 11.

If yes:

6. **How old were you when you were first admitted to hospital for the treatment of a mental illness?** _____ **Years**

7. **How many times have you been hospitalized for the treatment of a mental illness?** _____ **Times**

8. **How many weeks overall do you estimate you were admitted to hospital for the treatment of a mental illness?**
   _____ **Weeks**

9. **Were any of these hospitalizations against your will or involuntary?**
   ☐ Yes ☐ No

10. **If yes, how many?** _____Times

11. **Have you ever received treatment for a mental illness through an outpatient program?** ☐ Yes ☐ No

12. **If yes, please indicate the number of years, months or weeks (as applicable) that you were in an outpatient program.**
    _____ Years _____ Months _____ Weeks

13. **Do you receive financial assistance from AISH (Assured Income for the Severely Handicapped)?** ☐ Yes ☐ No

Some people may find that friends and associates treat them differently once they find out they have a mental illness. The following questions deal with your opinions and attitudes on a variety of situations where people with mental illness interact with other people. A subsequent section will focus on your personal experiences dealing with a mental illness.

PLEASE MARK WHETHER YOU AGREE OR DISAGREE WITH EACH OF THE FOLLOWING STATEMENT.

14. **I believe most people feel afraid to have a conversation with someone who had a mental illness.**
    ☐ Agree ☐ Disagree ☐ Not Sure

15. **I think most people would be uncomfortable about working on the same job with someone who had a mental illness.**
    ☐ Agree ☐ Disagree ☐ Not Sure

16. **I believe most people would maintain a friendship with someone who had a mental illness.**
    ☐ Agree ☐ Disagree ☐ Not Sure

17. **I think most people would feel uncomfortable about rooming with someone who has a mental illness.**
    ☐ Agree ☐ Disagree ☐ Not Sure

18. **I believe most people would accept someone who has a mental illness as a close friend.**

❒ Agree ❒ Disagree ❒ Not Sure

19. **I think most people would be reluctant to date someone who has a mental illness.**

❒ Agree ❒ Disagree ❒ Not Sure

20. **I believe most people would marry someone with a mental illness just as they would anyone.**

❒ Agree ❒ Disagree ❒ Not Sure

21. **I think most people would feel ashamed if others knew that someone in their family had been diagnosed with a mental illness.**

❒ Agree ❒ Disagree ❒ Not Sure

22. **I believe most people in my community, if they knew, would treat someone who has a mental illness just as they would treat anyone.**

❒ Agree ❒ Disagree ❒ Not Sure

23. **I think most people would be opposed to having a group home for 6-8 people with a mental illness in their neighbourhood.**

❒ Agree ❒ Disagree ❒ Not Sure

24. **I believe most people would be opposed to having a group home for 6-8 people with a mental illness next door.**

❒ Agree ❒ Disagree ❒ Not Sure

25. **I believe most people think unfavourably of a person who has been in hospital for psychiatric treatment.**

❒ Agree ❒ Disagree ❒ Not Sure

26. **I believe most people think that a person who has a mental illness is a danger to themselves.**

❒ Agree ❒ Disagree ❒ Not Sure

27. **I believe most people think that a person who has a mental illness is dangerous to others.**

❒ Agree ❒ Disagree ❒ Not Sure

28. **I think most people believe that a person who has a mental illness is as intelligent as the average person.**

❒ Agree ❒ Disagree ❒ Not Sure

29. **I think most people believe that someone with a mental illness is as trustworthy as the average citizen.**

❒ Agree ❒ Disagree ❒ Not Sure

30. **I believe most people would take the opinions of someone who has a mental illness less seriously.**

❒ Agree ❒ Disagree ❒ Not Sure

31. **I think most people believe that if they entered a hospital for psychiatric care it would be a sign of personal failure.**

❒ Agree ❒ Disagree ❒ Not Sure

32. **I believe most employers would hire an individual who has a mental illness if he or she was qualified for the job.**

❒ Agree ❒ Disagree ❒ Not Sure

33. **I believe most people would not hire someone who has had mental illness to take care of a family member (e.g., child, person with disability, elderly parent) even if he or she had been well for some time.**

❒ Agree ❒ Disagree ❒ Not Sure

34. **I think most employers would pass over the application of someone who has a mental illness in favour of another applicant.**

❒ Agree ❒ Disagree ❒ Not Sure

THE NEXT SET OF STATEMENTS ASK ABOUT THE REACTIONS YOU RECEIVED WHEN OTHERS LEARNED THAT YOU HAVE A MENTAL ILLNESS.

IF YOU HAVE NEVER BEEN IN THE SITUATION DESCRIBED, PLEASE RESPOND BY MARKING THE BOX "DOES NOT APPLY".

35. **I have seen or read thing in the mass media (e.g., television, movies, books) about people with mental illness which I find hurtful or offensive.**

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

36. **I have been in situations where I have heard others say unfavourable or offensive things about people who have a mental illness.**
❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

37. **I have worried that others will view me unfavourably because I have a mental illness.**
❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

38. **I have been treated fairly by others who know I have a mental illness.**
❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

39. **I have been advised to lower my expectations for accomplishments in life because I have a mental illness.**
❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

40. **Friends who learned I have a mental illness have been supportive.**
❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

41. **I believe I have been treated as less competent by others when they learned I have a mental illness.**
❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

42. **Family members who learned I have a mental illness have been supportive.**
❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

43. **I have been shunned or avoided by others when it was revealed that I have a mental illness.**
❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

44. **I have been advised by health professionals to conceal my mental illness to avoid rejection and discrimination.**
❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

45. **I believe I have been turned down for employment which I was qualified when it was revealed that I have a mental illness.**
❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

46 **Co-workers and/or supervisors at work were supportive when they learned I have a mental illness.**
❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

47. **I have lied on written applications (for job, licenses, housing, school, etc.) that I had a mental illness for fear that information would be used against me.**

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

48. **I have had difficulty renting other housing when it was known that I have a mental illness.**

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

49. **I have been excluded from volunteer activities outside the mental health field when it was known that I have a mental illness.**

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

50. **I have been excluded from volunteer activities within the mental health field when it was known that I have a mental illness.**

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

51. **Leaders within my religious community have been helpful when they learned of my mental illness.**

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

52. **The fact that I have a mental illness has been used against me in non-criminal legal proceedings (such as child custody or divorce disputes).**

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

53. **I have been treated fairly by law enforcement officers when they learned I have a mental illness.**

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

54. **I have been treated fairly when I have used hospital emergency services for my mental illness.**

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

PLEASE MARK WHETHER YOU AGREE OR DISAGREE WITH EACH OF THE FOLLOWING STATEMENTS.

55. **The best thing to do is to keep my diagnosis of a mental illness a secret.**

❒ Agree ❒ Disagree ❒ Not Sure

56. **There is no reason for a person to hide the fact that he or she had a mental illness.**

❒ Agree ❒ Disagree ❒ Not Sure

57. **I often feel the need to hide the fact that I have had psychiatric treatment.**
❒ Agree ❒ Disagree ❒ Not Sure

58. **I have avoided telling others outside my immediate family that I have a mental illness.**
❒ Agree ❒ Disagree ❒ Not Sure

59. **If I had a close relative who had been treated for a mental illness, I would advise him or her not to tell anyone about it.**
❒ Agree ❒ Disagree ❒ Not Sure

60. **In order to get employment I believe that I will have to hide my history of treatment for a mental illness.**
❒ Agree ❒ Disagree ❒ Not Sure

61. **I've found that it's best to help the people close to me understand what psychiatric treatment is like.**
❒ Agree ❒ Disagree ❒ Not Sure

62. **If I thought a friend was uncomfortable with me because I had a mental illness, I would try to educate him or her about my illness.**
❒ Agree ❒ Disagree ❒ Not Sure

63. **If I thought an employer felt reluctant hiring a person who had a mental illness, I would try to explain to him or her that most people with a mental illness are good workers.**
❒ Agree ❒ Disagree ❒ Not Sure

64. **I would participate in an organized effort to teach the public more about mental illness.**
❒ Agree ❒ Disagree ❒ Not Sure

65. **After I started treatment for my mental illness, I often found myself educating others about my illness.**
❒ Agree ❒ Disagree ❒ Not Sure

66. **It is easier for me to be friendly with people who have or had a mental illness.**
❒ Agree ❒ Disagree ❒ Not Sure

67. **If I thought that someone I knew held negative opinions about people with a mental illness, I would try to avoid them.**

❒ Agree ❒ Disagree ❒ Not Sure

68. **If I was looking for a job and received an application, which asked about a history of psychiatric treatment, I would complete it.**

❒ Agree ❒ Disagree ❒ Not Sure

69. **If I thought an employer was reluctant to hire a person with a history of a mental illness, I wouldn't apply for the job.**

❒ Agree ❒ Disagree ❒ Not Sure

70. **If I believed that a person I knew thought unfavourably about me because I have a mental illness, I would try to avoid him or her.**

❒ Agree ❒ Disagree ❒ Not Sure

71. **I have claimed to have a different diagnosis so to protect myself from possible rejection.**

❒ Agree ❒ Disagree ❒ Not Sure

72. **When I meet people for the first time, I make a special effort to keep the fact that I have been in psychiatric treatment to myself.**

❒ Agree ❒ Disagree ❒ Not Sure

73. **I am reluctant to develop new friendships in fear of being rejected because I have a mental illness.**

❒ Agree ❒ Disagree ❒ Not Sure

74. **Individuals who have had a mental illness are able to fit into society.**

❒ Agree ❒ Disagree ❒ Not Sure

PLEASE CHECK ONE RESPONSE FOR EACH OF THE FOLLOWING QUESTIONS.

75. **What is your current marital status?**

❒ Single (never married)
❒ Common-law
❒ Married
❒ Separated
❒ Divorced
❒ Widowed

76. Do you live...?

- ❒ Alone
- ❒ With your spouse or common-law partner
- ❒ With your parents or siblings
- ❒ With your spouse or common-law partner and your parents or siblings
- ❒ With others
- ❒ Other Please specify _____

77. Do you live in...?

- ❒ Your own home — Is your home a...? ❒ House ❒ Condominium
- ❒ A rented home — Is your home a...? ❒ House ❒ Condominium ❒ Apartment
- ❒ In your family's (parents or siblings) home
  Do you share some of the costs? ❒ Yes ❒ No
- ❒ In your friend's home
  Do you share some of the costs? ❒ Yes ❒ No
- ❒ Sheltered accommodation
- ❒ Group home
- ❒ Other Please specify _____

78. What is the last grade of elementary or high school you completed?

Grade _____

79. At what age did you complete this grade? _____ Years

80. Have you attended technical, trade, or vocational school? ❒ Yes ❒ No

If yes, have you received a diploma? ❒ Yes ❒ No

81. Have you attended university? ❒ Yes ❒ No

If yes, have you received a degree? ❒ Yes ❒ No

If yes, what was the last degree you received?

- ❒ Bachelor's
- ❒ Master's
- ❒ Doctorate's

82. Are you currently employed? ❒ Yes ❒ No

IF NOT, GO TO QUESTION NUMBER 86.

If yes:

83. Are you employed...?

- ❒ Full-time
- ❒ Part-time
- ❒ Casual (no benefits)
- ❒ Contract

84. What is your job or occupation? _____

_____

85. Do you use your education in your present work?

❒ Yes ❒ No

86. Are you currently...? (Check as many as apply.)

- ❒ A homemaker
- ❒ A student
- ❒ A volunteer
- ❒ Retired
- ❒ Unable to work because of my mental health problems
- ❒ Unable to work because of other illness
- ❒ Unable to work because of disability from injury

87. Do you attend religious services? ❒ Yes ❒ No

If yes:

88. How often do you attend?

- ❒ One or more times per week
- ❒ Less than once a week but more than once a month
- ❒ Once a month or less

89. Do you consider yourself?

- ❒ Christian
- ❒ Jewish
- ❒ Hindu
- ❒ Muslim
- ❒ Other Please specify_____

Additional comments:

THANK YOU VERY MUCH FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE!!

PLEASE RETURN IT TO THE INVESTIGATOR

Appendix D

Questionnaire Draft 1
With Comments from Expert Panel and Planned Revisions

Overview:

- *Comments made by the expert panel are summarized below following the template of the questionnaire.*
- *The panellists were asked:1) Is the question appropriate for the intended purpose? Yes, No; 2) Does the question address a relevant and important topic? (One = important & relevant, three = of little benefit).*
- *Responses were noted if the panellist answered No to Q1 or "2" or "3" to Q2. All comments were recorded.*
- *Panellists were each assigned a unique alphanumeric code. The letter code represents a panellist category:*
  - *E - Expert panellist,*
  - *P - Professional research or clinician,*
  - *A - Mental health service administrator,*
  - *C - Consumer or consumer group representative, and*
  - *L - Industry liaison.*
- *An action plan and rationale for the decision was noted.*

Participant No._____

We appreciate your co-operation in the development of this questionnaire. It is being devised to learn about the social effects of having a mental illness from the consumers' viewpoint. This questionnaire will undergo a number of tests to improve the questions and format. The answers and feedback you provide are valued. An investigator will be available to you while you are completing this questionnaire to assist you with any questions you may have and to receive any feedback you would like to provide. We are aware that the questions ask for personal information; be assured that your name will not be associated with your answers under any circumstances.

Comments:

- *The assurance that "your name will not be associated with your answers under any circumstances." May in itself be stigmatizing, suggesting that identification as a person with mental illness is something to be greatly avoided. What about just "will not be associated with your answers" without "your written consent to do so." (E25P)*
- *I would discourage the current usage of the "consumer" in the preamble - I think you mean consumer of services (and the wording is second nature to those involved in consumer advocacy, but not necessarily to the general public) - but it sounds like consumer of mental illness with the way that it is worded. This needs to be clarified, or replaced with a term like: "persons with mental illness." (E29P)*

Action:

- *Revision:*

We appreciate your co-operation in the development of this questionnaire. It is being devised to learn about the social effects of having a mental illness from the viewpoint of persons with a mental illness. This questionnaire will undergo a number of tests to improve the questions and format. Your answers and feedback will help with this revision process. We are aware that the questions ask for personal information; be assured that your name will not be associated with your answers without your written consent to do so.

1. Are you ☐ male or ☐ female?

Comments:

- *"2" (E27A)*

2. What year were you born? 19_____.

Comments:

- *"2" (E11A, 27A)*
- *Regarding Q2 and Q3: You get information on year of birth and date of diagnosis. You may wish to consider such variables as (calendar) year of diagnosis, age at interview etc. Be careful that there is a place on the questionnaire to record the date of the interview, as this would be required to calculate exact age at interview - why not record birth date rather than year of birth (this would minimize the error in calculating age at interview)? Perhaps, though, this is a confidentiality issue, because DOB could be used for record linkage. If your Participant # includes the date of the interview in its calculation procedure (I always do this) you can use DOB to calculate age at interview electronically. (E29P)*

Action:

- *Revision: What is your date of birth?*

_____19_____ _____ _____
(year) (month) (day)

Rationale:

- *Improve accuracy.*

3. What age were you when you were diagnosed with a mental illness?

_____ Years

Comments:

- *If you reverse Q3 and Q4, this will focus them on current diagnosis. (E6P)*
- *Not appropriate for intended purpose. "2" This may be a difficult question because may not remember <u>when</u> diagnosed appropriately versus when life began changing. Perhaps ask when began treatment. Are you attempting to gather onset data or length of years living with/receiving treatment for an illness? (E10A)*
- *This may not, however, be the same age at which the illness began. (E25P)*

- *"2" (E27A)*

Action:

- *Revision: What year did you begin psychiatric treatment?*
  _____19_____

Rationale:

- *Objective of question was to ascertain length of time in treatment.*

4. **What is your current psychiatric diagnosis as defined by a doctor?**

- ☐ Schizophrenia
- ☐ Psychoses
- ☐ Depression
- ☐ Manic Depression
- ☐ Anxiety Disorder
- ☐ Other Please specify_____

Comments:

- *Not appropriate for intended purpose. Mixes diagnostic systems. ?Bipolar (E4P)*
- *Add bipolar beside major depression. (E7A)*
- *Wonder about the diagnosis of psychoses. Will that be seen to overlap? (E21L)*
- *What does "psychosis" add? (It should read "psychoses.") Why by a doctor? There are other professionals involved? (E24P)*
- *Will you allow for more than one diagnosis? "Psychoses" seems redundant with the others. (E25P)*
- *Not appropriate for the intended purpose. Should substance-use disorders be in there too? Anxiety disorder is a broad term, and rarely used outside of professional circles - by far the most common ones are phobias, and most people wouldn't know that a phobia is an anxiety disorder. Also, there may need to be some explanation of the term psychoses (which is plural or psychosis) - as mood disorders can be (and Schizophrenia is) a psychosis. Should mention Bipolar Disorder as a synonym for Manic Depression. (E29P)*

Action:

- *Deletion*

Rationale:

- *Unnecessary. Determining diagnosis will be achieved during selection based on inclusion/exclusion criteria and confirmed during the consent process.*

5. **Have you ever been admitted to hospital to receive treatment for a mental illness.**

☐ Yes ☐ No

Comments:

- *Not appropriate for intended purpose. Does admitted mean inpatient, outpatient, or emergency? (E4P)*

- *Relevant if you ask when first signs were. (E7A)*
- *"2" (E11A)*
- *Regarding Q5 through Q11: Consider asking whether it was a mental hospital, Psychiatric Unit in general hospital (or non-psychiatric unit) - increase emphasis on general hospital care was intended to decrease stigma. Hospitalization: A major concern historically has been the issue of institutionalization - it is possibly relevant to stigma: I wonder if there should be a question about the total duration of time in hospital. (E29P)*

Action:

- *Revision: Have you ever stayed in hospital to receive treatment for a mental illness.*
- *Addition:*

If yes, did you stay in a...?

- ☐ *Mental hospital*
- ☐ *Psychiatric ward in a general hospital*
- ☐ *Non-psychiatric ward in a general hospital*

Rationale:

- *Improve accuracy.*

IF NO, GO TO QUESTION NUMBER 11.

If yes:

6. **How old were you when you were first admitted to hospital for the treatment of a mental illness?** _____ Years

Comments:

- *"3" With need to reduce eliminate this one. Q3 is probably adequate. (E6P)*
- *"2" (E7A, 24P, 27A)*
- *"2" Again may not be aware of mental illness at the time. (E10A)*
- *"2" Should a distinction be made between initial admission and total? (E21L)*
- *You could lose either Q3 or Q6. (E26P)*

Action:

- *Deletion.*

Rationale:

- *Unnecessary; Q3 adequate addresses topic.*

7. **How many times have you been hospitalized for the treatment of a mental illness?** _____ Times

Comments:

- *"2" (E6P, 7A, 11A, 20A, 24P, 27A)*

Action:

- *Deletion.*

Rationale:

- *Need to reduce total items.*

If yes:

8. **How many weeks overall do you estimate you were admitted to hospital for the treatment of a mental illness?**

   _____ Weeks

   Comments:

   - *Suggest: ...spent in...(E4P)*
   - *Not appropriate for intended purpose. "3" Omit. If hospitalized for 3 years will be tough for patient to convert to weeks. (E6P)*
   - *"2" (E8A, 11A, 20A, 24P, 26P, 27A)*
   - *Not appropriate for intended purpose. "3" All-inclusive? Data will be highly questionable. (E10A)*
   - *Poorly worded. How many total weeks have you spent in hospital? (E14C)*
   - *"A patient in" rather than "admitted to." (E23C)*
   - *"2" This (# of weeks) may be difficult for respondents to recall. (E25P)*

   Action:

   - *Deletion.*

   Rationale:

   - *Too difficult to recall and estimate.*

9. **Were any of these hospitalizations against your will or involuntary?**

   ☐ Yes ☐ No

   Comments:

   - *"3" (E4)*
   - *"2" (E6, 10, 27A)*
   - *Ask if ever certified under the Mental Health Act. (E8)*
   - *"Or involuntary" redundant? (E23C)*
   - *Not appropriate for the intended purpose. "3" In the US, voluntary vs. involuntary are often hard to separate. (E25P)*

   Action:

   - *None.*

   Rationale:

   - *From the literature stigma due to hospitalization is greater with involuntary commitment than voluntary hospitalization.*

10. **If yes, how many?** _____Times

Comments:

- *Not appropriate of intended purpose. "3" (E6P, 26P)*
- *Hard to find question. (E7A)*
- *"2" (E10A, 11A, 23C, 24P, 27A)*
- *People may have trouble remembering. (E14C)*

Action:

- *Deletion.*

Rationale:

- *Need to reduce questions.*

11. **Have you ever received treatment for a mental illness through an outpatient program?** ☐ Yes ☐ No

Comments:

- *Not appropriate of intended purpose. "3" (E6P)*
- *"2" (E7A, 20A, 24P)*
- *"3" What is "outpatient"? From facility, mental health clinics, agencies? (E10)*
- *"Outpatient programs" (E23C)*
- *Not appropriate of intended purpose. "3" You know the answer already. (E26P)*

Action:

- *Deletion.*

Rationale:

- *Unnecessary.*

12. **If yes, please indicate the number of years, months or weeks (as applicable) that you were in an outpatient program.**

_____ Years _____ Months _____ Weeks

Comments:

- *Not appropriate of intended purpose. "3" (E6P)*
- *"3" Pick one. (E10A)*
- *"2" (E11A, 20A, 27A)*
- *"3" (E24P)*
- *"2" Again, this may be difficult for respondents to estimate. (E25P)*
- *Not appropriate of intended purpose. "3" Too similar to Q3 and Q6. (E26P)*
- *One level of care not included is Day Hospital Program. (E29P)*

Action:

- *Deletion.*

Rationale:

- *Too difficult to recall and estimate.*

13. **Do you receive financial assistance from AISH (Assured Income for the Severely Handicapped)?** ❒ Yes ❒ No

Comments:

- *Reword as disability pension. AISH is an "Alberta" term. (E6P)*
- *"2" Are you interested in other incomes? (E9A)*
- *"2" (E11A, 14C, 26P)*
- *Another relevant question is: What other source of income do you have if you do not have AISH. (S19C)*
- *Not appropriate for intended purpose. "3" (E27A)*

Action:

- *Deletion.*

Rationale:

- *Receiving financial assistance is stigmatizing however; this item does not tap the issue adequately. Secondly, it is not appropriate to elaborate in the context of this questionnaire.*

Some people may find that friends and associates treat them differently once they find out they have a mental illness. The following questions deal with your opinions and attitudes on a variety of situations where people with mental illness interact with other people. A subsequent section will focus on your personal experiences dealing with a mental illness.

PLEASE MARK WHETHER YOU AGREE OR DISAGREE WITH EACH OF THE FOLLOWING STATEMENT.

Comments regarding instruction box:

- *Explanation after question 13 is too long. Format like box on after question 34, e.g., "A subsequent section ... illness" is not necessary. (E6P)*

Action:

- *Revision: Combine boxes and reword:*

THE FOLLOWING STATEMENTS DEAL WITH YOUR OPINIONS.

PLEASE MARK WHETHER YOU AGREE OR DISAGREE WITH EACH OF THE FOLLOWING STATEMENTS.

Rationale:

- *Shorten.*

Comments regarding section:

- *Some of these are worded 'negative', some 'positive' - is there a reason for this? Will the 'suggested' response bias the answers? May want to do a comparison into items changed from 'positive' to 'negative' and vice versa. There is redundancy; meaning items are rather similar. Consider 'forcing' answer instead of the neutral escape answer. (E4P)*
- *This section overall is less important than Discrimination as it seems it describes "actual "first hand experiences. (E9A)*

- *Suggest a four or 5- point scale without the "not sure." (E24P)*
- *Regarding Q14 through Q34: Excellent questions, I like them all. I'd consider addition of a 4th category - it would seem that a person could have a neutral opinion - neither agreeing nor disagreeing, which is (maybe) different from being 'not sure' which implies uncertainty rather than neutrality. I am not very certain about this - but it warrants some consideration?? It has always seemed to me that a part of stigma is an anxiety related to a lack of self-confidence - in your model - a person may have the experience of rejection and devaluation, leading to stigmatization, or they may have a fear of rejection and devaluation that causes them to avoid circumstances where the fears might become reality. This is why I worry about the limited response options in this section. A person might believe that most people would accept them, or that most people would not accept them. But when they say "not sure," its unclear to me whether they are saying that they are unsure what proportion would/would not accept them, or that they have a great uncertainty about what others think of them. (E29P)*

Action:

- *Use 4-point scale: Definitely agree, agree, disagree, and definitely disagree.*

Rationale:

- *Studies suggest that the minimum number of categories used by raters should be in the region of five to seven. The number of categories depend upon the ability of the raters to discriminate choices without be too few to lose information. An even number of categories was selected to force the raters to commit themselves to one side or the other. The choice becomes four or six categories; four was selected to keep the options concise.*

14. I believe most people feel afraid to have a conversation with someone who had a mental illness.

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *"Has" instead of "had"? (E6P)*
- *"To talk to" not "have a conversation"! (E10A)*
- *"Has" - "had" is a bit ambiguous. (E23C)*
- *Add, "would" (feel) to be consistent with wording of other items. (E25P)*
- *"2" (E27A)*

Action:

- *Revision: I believe most people would feel afraid to talk to someone who has a mental illness.*

Rationale:

- *Simplify wording and change tense.*

15. **I think most people would be uncomfortable about working on the same job with someone who had a mental illness.**

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *"2" Depends on job. (E7A)*
- *"2" (E11A)*
- *"Has" - "had" is a bit ambiguous. (E23C)*

Action:

- *Revision: I think most people would be uncomfortable working with someone who has a mental illness.*

Rationale:

- *Clarity, consistency.*

16. **I believe most people would maintain a friendship with someone who had a mental illness.**

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *Once they found out about the mental illness? (E8A)*
- *"2" "Maintain" (E10A)*
- *"2" (E11A)*
- *Not appropriate for intended purpose. "3" Question could have many different meanings, how old is this friendship, how close, what damage has the illness done to the friendship, did friend see person in acute stage, etc. (E14C)*
- *Positive statement. (E21L)*
- *"Has" - "had" is a bit ambiguous. (E23C)*
- *Could be confused as asking about making friends as opposed to keeping them. (E25P)*

Action:

- *Revision: I believe most people would maintain a friendship with someone who has a mental illness once they found out about the mental illness.*

Rationale:

- *Clarity, consistency.*

17. **I think most people would feel uncomfortable about rooming with someone who has a mental illness.**

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *Rooming versus living with? (E6P)*
- *"2" "Rooming" (E10A)*
- *Wording has changed from "had" a mental illness to "has" an illness. (E25P)*

Action:

- *Revision: I think most people would feel uncomfortable living with someone who has a mental illness.*

Rationale:

- *Clarity, consistency.*

18. **I believe most people would accept someone who has a mental illness as a close friend.**

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *Almost same as Q16. (E5L)*
- *"2" (E6P, 11A)*
- *"3" Redundant to Q16. (E10A)*
- *Positive statement. (E21L)*
- *But seems redundant with Q16. (E25P)*
- *Not appropriate for intended purpose. "3" Redundant to Q16. (E27A)*

Action:

- *Deletion.*

Rationale:

- *Redundant with Q16.*

19. **I think most people would be reluctant to date someone who has a mental illness.**

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *Unless they also have a mental illness. (E8A)*
- *"2" "Reluctant" (E10A)*
- *Again "has" vs. had". (E25P)*

Action:

- *Revision: I think most people would not date someone who has a mental illness.*

Rationale:

- *Simplify wording.*

20. **I believe most people would marry someone with a mental illness just as they would anyone.**

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *Reword last part of sentence. (E6P)*
- *"2" (E11A)*
- *Suggest wording change - add ... anyone without a mental illness. (E20A)*
- *Superfluous "just as they would anyone" (E21L)*
- *Remove "just as they would anyone." (E24P)*
- *"... As they would anyone without a mental illness." (E26P)*

Action:

- *Revision: I believe most people would not marry someone who has a mental illness.*

Rationale:

- *Clarity, consistency.*

21. **I think most people would feel ashamed if others knew that someone in their family had been diagnosed with a mental illness.**

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *Unclear wording. (E6P)*
- *"2" (E11A)*

Action:

- *Revision: I think most people would feel ashamed if others knew that someone in their family has a mental illness.*

Rationale:

- *Simplify wording and change tense.*

22. **I believe most people in my community, if they knew, would treat someone who has a mental illness just as they would treat anyone.**

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *"2" A bit vague. (E5L)*
- *Reword. (E6P)*
- *"2" (E9A, 11A)*
- *Not appropriate for intended purpose. "3" Seems redundant to total of all other questions. (E21L)*
- *Not appropriate for intended purpose. "3" Too non-specific. And treating them the same might not be a good thing. (E25P)*
- *"2" "...If they knew someone had a mental illness; they would treat him or her the same as anyone else". (E26P)*

Action:

- *Deletion.*

Rationale:

- *Too broad.*

23. **I think most people would be opposed to having a group home for 6-8 people with a mental illness in their neighbourhood.**

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *Regarding Q23 and Q24P: Eliminate one of the two. Too much concentration required to differentiate these two questions. (E6P)*
- *Redundant - chose Q24. (E7A)*

- *Do you need this fine a distinction between neighbourhood and next door. Q24 = "3". (E9A)*
- *"Opposed" (E10A)*
- *Q24 somewhat redundant to Q23. (E20A)*
- *Regarding Q34 and Q24: seems a fine distinction between these two. (E21L)*
- *But probably do not need both Q23 and Q24. (E25P)*

Action:

- *Revision: I think most people would be against having a group home for 6-8 people who have a mental illness in their neighbourhood. Delete question 24.*

Rationale:

- *Simplify wording.*

24. **I believe most people would be opposed to having a group home for 6-8 people with a mental illness next door.**

❒ Agree ❒ Disagree ❒ Not Sure

Action:

- *Deletion.*

Rationale:

- *Redundant – too close to Q23.*

25. **I believe most people think unfavourably of a person who has been in hospital for psychiatric treatment.**

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *Eliminate "hospital." (E6P)*
- *Not appropriate for intended purpose. "2" "unfavourably." (E10A)*
- *"2" (E11A)*
- *A comparable question for outpatient treatment might be appropriate. (E25P)*

Action:

- *Deletion.*

Rationale:

- *Redundant – too close to Q31.*

26. **I believe most people think that a person who has a mental illness is a danger to themselves.**

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *"2" (E7A)*
- *"Has" Number does not agree in wording: person - themselves. Also, "likely to hurt themselves" is clearer than "a danger to ..." (E25P)*

Action:

- *Deletion.*

Rationale:
- *Redundant.*

27. **I believe most people think that a person who has a mental illness is dangerous to others.**

❒ Agree ❒ Disagree ❒ Not Sure

Comments:
- *"2" (E11A)*
- *Again, dangerous vs. likely to harm. (E25P)*

Action:
- *Revision: I believe most people think that a person who has a mental illness is likely to harm others.*

Rationale:
- *Clarity.*

28. **I think most people believe that a person who has a mental illness is as intelligent as the average person.**

❒ Agree ❒ Disagree ❒ Not Sure

Comments:
- *"2" (E7A)*
- *"2" Positive statement. (E21L)*

Action:
- *Revision: I think most people would believe that a person who has a mental illness is intelligent.*

Rationale:
- *Clarity and consistency.*

29. **I think most people believe that someone with a mental illness is as trustworthy as the average citizen.**

❒ Agree ❒ Disagree ❒ Not Sure

Comments:
- *Not relevant for the intended purpose. "3" Very subjective question - trust to keep secret - trust to remember? (E7A)*
- *"2" (E10A, 11A)*
- *This seems to overlap with Q30. (E25P)*

Action:
- *Deletion*

Rationale:
- *Redundant with Q33.*

30. **I believe most people would take the opinions of someone who has a mental illness less seriously.**

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *"2" (E7A, 10A)*
- *"2" Seems broad. (E21L)*
- *But unclear what less seriously means - treat them humorously, disregard person or disregard/minimize the illness? (E25P)*

Action:

- *Revision: I believe most people would disregard the opinions of someone who has a mental illness.*

Rationale:

- *Clarity.*

31. I think most people believe that if they entered a hospital for psychiatric care it would be a sign of personal failure.

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *"2" (E10A, 11A)*
- *Believe that "entering a hospital for psychiatric care would be a sign of personal failure." (E25P)*

Action:

- *Revision: I think most people believe that entering a hospital for psychiatric care would be a sign of personal failure.*

Rationale:

- *Clarity.*

32. I believe most employers would hire an individual who has a mental illness if he or she was qualified for the job.

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *Regarding Q32 through Q34: Reduce the number of questions? I see the distinctions. How important is this versus need to decrease length? (E6P)*
- *Better than the last one related to employment. (E10A)*
- *"2" (E11A)*

Action:

- *Deletion.*

Rationale:

- *Redundancy, retain Q34.*

33. I believe most people would not hire someone who has had mental illness to take care of a family member (e.g., child, person with disability, elderly parent) even if he or she had been well for some time.

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *"2" (E9A, 10A)*

- *"2" The addition of "even if he or she had been well for some time" is unnecessary. (E21L)*
- *Too wordy. (E24P)*
- *Now "has had" vs. "has" or "had." (E25P)*

Action:

- *Revision: I believe most people would not hire someone who has a mental illness to take care of a family member (e.g., child).*

Rationale:

- *Shorten.*

34. I think most employers would pass over the application of someone who has a mental illness in favour of another applicant.

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *"2" Q32 covers this. (E10A)*
- *If this is a check on Q32, I would separate them more. (E25P)*
- *Not appropriate for intended purpose. "3" Redundant to Q32. (E27A)*

Action:

- *No change.*

THE NEXT SET OF STATEMENTS ASK ABOUT THE REACTIONS YOU RECEIVED WHEN OTHERS LEARNED THAT YOU HAVE A MENTAL ILLNESS.

IF YOU HAVE NEVER BEEN IN THE SITUATION DESCRIBED, PLEASE RESPOND BY MARKING THE BOX "DOES NOT APPLY".

Comments:

- *Regarding Q35 - 42: Some rather similar items (E4P)*
- *Regarding section: "Does Not Apply" and "Never" seem to ask the same questions. Regarding Q35, 36, 39 - 45, 48 - 51: These questions would be better answered if had number selection i.e., (1-5) (5-20) (20+). (E7A)*
- *Regarding Q35-41: Is the random order of these questions rather than a grouping into related issues intentional? (E23C)*
- *Regarding Q35-38: Unlike other questions in this series, these refer to "others" not specific groups e.g., co-workers, family. (E29P)*
- *Regarding Q35-44: I worry about the "Does not apply" category in these questions, as they would seem to apply to everyone. In Q45-54: consider some way to clarify that Does Not Apply means such things as "I've not recently applied for employment" as it stands, there may be some risk that subjects will select these options if they are unsure of the answer. In view of this, you could also include a category for do not know/unsure - hence, distinguishing it from not applicable. (E29P)*

Action:

- *Create new section: Insert instruction box stating "Please check the most appropriate response. Group: Q35, 36, 39, and 44. Use the following response categories: never, seldom, sometimes, and often.*
- *Reorganize other questions.*

35. I have seen or read thing in the mass media (e.g., television, movies, books) about people with mental illness which I find hurtful or offensive.

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

Comments:

- *Eliminate "mass." (E6P)*
- *"Thing" should probably read "something." (E20A)*
- *"Thing"/ seems odd to start with / mass media. (E21L)*
- *Things (E23C)*
- *Delete "Does not apply". "Thing" should be plural. (E24P)*
- *Not appropriate for intended purpose. "3" Not relevant. (E27A)*
- *Not appropriate for intended purpose. I wonder if there should be a distinction between entertainment & news media. (E29P)*

Action:

- *Revision: Within the last 4 months, I have seen news stories on TV or read articles in the newspapers about people who have a mental illness which were hurtful or offensive.*

Rationale:

- *Needs temporal orientation. Improve clarity and specificity.*

36. I have been in situations where I have heard others say unfavourable or offensive things about people who have a mental illness.

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

Comments:

- *"Unfavourable" "offensive" (E10A)*
- *"2" (E11A)*
- *Delete "Does not apply". (E24P)*
- *Not appropriate for intended purpose. "3" Not relevant. (E27A)*
- *Should that specify social situations? (E29P)*

Action:

- *Revision: Within the last 4 months, I have heard people say offensive things about people who have a mental illness.*

Rationale:

- *Needs temporal orientation. Improve clarity.*

37. I have worried that others will view me unfavourably because I have a mental illness.

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

Comments:
- *Delete "Does not apply". (E24P)*
- *Our factor analysis showed this to be a stigma expectation rather than experience. (E25P)*

Action:
- *Deletion.*

Rationale:
- *Unnecessary.*

38. I have been treated fairly by others who know I have a mental illness.

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

Comments:
- *Not relevant for the intended purpose. "3" Very subjective. (E7A)*
- *"2" Too broad? (E9A)*
- *"2" (E11A)*
- *Positive statement. (E21L)*
- *Not appropriate for intended purpose. "2" Too general, we did not find this a useful item. (E25P)*

Action:
- *Deletion.*

Rationale:
- *Too broad.*

39. I have been advised to lower my expectations for accomplishments in life because I have a mental illness.

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

Comments:
- *"Advised" (E10A)*
- *"2" (E11A, 26P)*

Action:
- *Revision: I have been advised by health care professionals to lower my expectations for accomplishments in life because I have a mental illness.*

Rationale:
- *Improve clarity.*

40. Friends who learned I have a mental illness have been supportive.

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

41. I believe I have been treated as less competent by others when they learned I have a mental illness.

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

Comments:
- *"2" (E7A)*

- *Not appropriate for the intended purpose. "2" Somewhat redundant. (E20A)*

Action:

- *Revision: I have been treated as less competent by others because I have a mental illness.*

Rationale:

- *Simplify wording.*

42. Family members who learned I have a mental illness have been supportive.

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

Comments:

- *Can friends and family go together? You are asking about personal support networks. (E10A)*
- *Positive statement. (E21L)*

Action:

- *No change*

43. I have been shunned or avoided by others when it was revealed that I have a mental illness.

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

Action:

- *Revision: I have been shunned or avoided by others because I have a mental illness.*

Rationale:

- *Simplify wording.*

44. I have been advised by health professionals to conceal my mental illness to avoid rejection and discrimination.

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

Comments:

- *Q44 and Q47 similar. (E4P)*
- *Not sure the purpose of this question. (E10A)*
- *"2" (E11A)*
- *Delete "to conceal." (E24P)*

Action:

- *Revision: I have been advised by health care professionals to conceal my mental illness to avoid rejection and discrimination.*

Rationale:

- *Improve clarity.*

45. I believe I have been turned down for employment, which I was qualified when it was revealed that I have a mental illness.

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

Comments:

- *Typographical error, Q45 should read "for which I was qualified". (E1P)*
- *When I revealed (E6P)*
- *"2" (E11A)*
- *"For which..." (E23C)*
- *Grammar. (E24P)*
- *Again, why "I believe". It is all consumer perception. Also, it should be "for which I was qualified". (E25P)*

Action:

- *Revision: I have been turned down for employment for which I was qualified when I revealed I have a mental illness.*

Rationale:

- *Grammar, improve consistency.*

46. Co-workers and/or supervisors at work were supportive when they learned I have a mental illness.

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

Comments:

- *"2" (E7A)*
- *Positive statement. (E21L)*

Action:

- *Revision: Co-workers and/or supervisors at work were supportive when I revealed I have a mental illness.*

Rationale:

- *Simplify and improve consistency.*

47. I have lied on written applications (for job, licenses, housing, school, etc.) that I had a mental illness for fear that information would be used against me.

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

Comments:

- *"2" May be seen as self-incriminating and therefore not answered. (E5L)*
- *This is a bit confusing in the wording. (E9A)*
- *"2" (E11A)*
- *I would change the word "lie" to mislead, given misinformation. (E21L)*
- *Grammar & wording. (E24P)*
- *Wording is confusing. How about "lied...on applications that asked if I had..." (E25P)*

Action:

- *Revision: I have lied on applications (for work, housing, etc.) that asked if I had a mental illness for fear that information would be used against me.*

Rationale:

- *Improve clarity.*

48. I have had difficulty renting other housing when it was known that I have a mental illness.

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

Comments:

- *"Other housing"? (E6P)*
- *Will people know what "other" housing is? (E9A)*
- *"Because" instead of "when it was know that" would be more direct. (E23C)*
- *Replace "other housing" with "a home." (E24P)*
- *Not clear what is meant by "other" housing. (E25P)*

Action:

- *Revision: I have had difficulty renting a home because I have a mental illness.'*

Rationale:

- *Simplify and improve clarity.*

49. I have been excluded from volunteer activities outside the mental health field when it was known that I have a mental illness.

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

Comments:

- *Not appropriate for intended purpose; "3" (E4P)*
- *Regarding Q49 and 50: Simplify into one or remove Q50? (E6P)*
- *Regarding Q49 and 50: Collapse to one item. (E9A)*
- *"2" (E11A)*
- *Regarding Q49 and 50: "2" Fine distinction necessary. Why not just volunteer activities? (E21L)*
- *"Because" instead of "when it was know that" would be more direct. (E23C)*
- *Replace "was" with "became." (E24P)*

Action:

- *Revision: I have been excluded from volunteer activities because I have a mental illness.*

Rationale:

- *Combine with Q50 into one question.*

50. I have been excluded from volunteer activities within the mental health field when it was known that I have a mental illness.

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

Comments:

- *Not appropriate for intended purpose; "3" (E4P)*
- *"Because" instead of "when it was know that" would be more direct. (E23C)*

Action:

- *Deletion*

Rationale:

- *Redundant with Q49.*

51. **Leaders within my religious community have been helpful when they learned of my mental illness.**

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

Comments:

- *Why leaders only? (E6P)*
- *Need to state the opposite e.g., leaders in religious community have not been helpful...? (E8A)*
- *Positive statement. (E21L)*
- *Does it need to be only "leaders"? What about other members of their faith community? (E25P)*

Action:

- *Revision: Leaders within my religious community have been helpful when I revealed I have a mental illness.*

Rationale:

- *Improve consistency.*

52. **The fact that I have a mental illness has been used against me in non-criminal legal proceedings (such as child custody or divorce disputes).**

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

Comments:

- *Simplify "non-criminal disputes." (E6P)*
- *Poor wording. (E10A)*

Action:

- *Revision: My mental illness was used against me in non-criminal disputes (i.e., child custody or divorce proceeding).*

Rationale:

- *Simplify wording.*

53. **I have been treated fairly by law enforcement officers when they learned I have a mental illness.**

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

Comments:

- *Regarding Q53 and Q54: Subjective "fairly" perhaps changes to more specific question i.e., officers were respectful, listened to respectfully by ER staff. (E7A)*
- *"Were aware" rather than "learned"? (E23C)*

Action:

- *Revision: I have been treated fairly by law enforcement officers when I revealed I have a mental illness.*

Rationale:

- *Improve consistency.*

54. I have been treated fairly when I have used hospital emergency services for my mental illness.

❒ Does Not Apply ❒ Never ❒ Sometimes ❒ Often

Comments:

- *"2" Fairly by whom? (E25P)*

Action:

- *Revision: I have been treated fairly by the nurses and doctors when I used hospital emergency services for my mental illness.*

Rationale:

- *Improve clarity.*

PLEASE MARK WHETHER YOU AGREE OR DISAGREE WITH EACH OF THE FOLLOWING STATEMENTS.

Comments regarding section:

- *Get rid of "not sure" or put it in the middle of a five -point scale. (E24P)*
- *I would look at the order of questions here: seem to be (1) secrecy, (2) education, and (3) withdrawal. Better to mix them up I would think. (E29P)*

Action:

- *Use 4-point scale: Definitely agree, agree, disagree, and definitely disagree.*

55. The best thing to do is to keep my diagnosis of a mental illness a secret.

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *Regarding Q55 through Q58 - similar items (E4P)*
- *Regarding Q55 and 56: Omit one of these, suggest Q56. (E6P)*
- *"2" (E11A)*
- *Regarding Q55 through Q57: Perhaps this is intentional, but the redundancy in these may make it confusing. (E21L)*
- *But the best thing to do for what? (E25P)*

Action:

- *Revision: I keep my diagnosis of mental illness a secret to prevent rejection.*

Rationale:

- *Regarding question 55 through 60: Distinction between items is too narrow therefore reduce. Revise to report rather than predict behaviour.*

56. There is no reason for a person to hide the fact that he or she had a mental illness.

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *"2" (E11A)*
- *"...He or she has had a ..." (E26P)*

Action:

- *Deletion.*

57. I often feel the need to hide the fact that I have had psychiatric treatment.

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *"The need to hide the fact" (E6P)*
- *"2" Q55 covers it. (E10A)*
- *"2" (E11A)*
- *Somewhat redundant to Q55 and 56. (E20A)*
- *1) Feeling the need is not the same as hiding it. 2) Mixing what the person endorses in principle and what her or she actually does. (E25P)*

Action:

- *Deletion.*

58. I have avoided telling others outside my immediate family that I have a mental illness.

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *Ask why? (E8A)*

Action:

- *Deletion.*

59. If I had a close relative who had been treated for a mental illness, I would advise him or her not to tell anyone about it.

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *"If my relative had psychiatric treatment, I would tell him/her...." (E6P)*
- *"2" (E11A)*
- *"3" - duplicates opinion expressed in Q55. (E23C)*
- *Again, predicting rather than reporting behaviour. (E25P)*

Action:

- *Deletion.*

60. In order to get employment I believe that I will have to hide my history of treatment for a mental illness.

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *"2" (E11A)*
- *Again, predicting rather than reporting behaviour. (E25P)*

Action:

- *Deletion.*

61. **I've found that it's best to help the people close to me understand what psychiatric treatment is like.**

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *Regarding Q61 through Q74: While theoretically I can understand splitting up questions on e.g., work/employment, I think this makes questionnaire more difficult for person with schizophrenia as he/she has to switch sets more often. Grouping related questions together may be helpful. Will also help you see if you are duplicating/redundant. (E6P)*
- *Not appropriate for intended use. "3" Confusing question since there are so many different treatments. The person would probably want to educate on the disorder itself rather than treatment. (E14C)*
- *"2" (E21L, 26P)*
- *Not appropriate for intended purpose. "2" Not sure this question is relevant. (E20A)*
- *Regarding Q61 through 65: There are only two or three coping mechanisms being tapped here. Do you need all these questions? (E24P)*
- *Regarding Q61 and 62: Needs further explanation. (E21L)*

Action:

- *Revision: I try to explain my illness to others to help them understand.*

Rationale:

- *Regarding questions 61 through 66: Distinction between questions is too narrow. Reduce questions. Revise to report rather than predict behaviour.*

62. **If I thought a friend was uncomfortable with me because I had a mental illness, I would try to educate him or her about my illness.**

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *"2" (E7A)*
- *Again, predicting rather than reporting behaviour. (E25P)*

Action:

- *Deletion.*

63. **If I thought an employer felt reluctant hiring a person who had a mental illness, I would try to explain to him or her that most people with a mental illness are good workers.**

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *"2" (E7A)*
- *Not appropriate for the intended purpose. Ask instead if... I would try to explain to him what mental illnesses are. (E8A)*
- *Again, predicting rather than reporting behaviour. (E25P)*

Action:
- *Deletion.*

64. **I would participate in an organized effort to teach the public more about mental illness.**

❒ Agree ❒ Disagree ❒ Not Sure

Comments:
- *Again, predicting rather than reporting behaviour. (E25P)*

Action:
- *Deletion.*

65. **After I started treatment for my mental illness, I often found myself educating others about my illness.**

❒ Agree ❒ Disagree ❒ Not Sure

Comments:
- *"2" After treatment for your mental illness how long was it before you started educating others about your illness? (E8A)*

Action:
- *Deletion.*

66. **It is easier for me to be friendly with people who have or had a mental illness.**

❒ Agree ❒ Disagree ❒ Not Sure

Comments:
- *Not appropriate for intended purpose. "3" (E4P)*
- *"2" (E11A)*
- *Not appropriate for intended purpose. "Easier" than what. Is this a coping mechanism? (E24P)*
- *Not appropriate for intended purpose. "2" (E25P)*
- *"...Have or have had a..." (E26P)*

Action:
- *Deletion.*

Rationale:
- *Not a coping mechanism.*

67. **If I thought that someone I knew held negative opinions about people with a mental illness, I would try to avoid them.**

❒ Agree ❒ Disagree ❒ Not Sure

Comments:
- *"2" (E11A)*
- *Regarding Q67 through Q73: Could the person complete it and lie? (E24P)*
- *Again, predicting rather than reporting behaviour. (E25P)*

Action:
- *Revision: I avoid people who have negative opinions about mental illness.*

Rationale:

- *Revise to report rather than predict behaviour.*

68. If I was looking for a job and received an application which asked about a history of psychiatric treatment, I would complete it.

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *"2" (E10A)*
- *"3" (E11A)*
- *Not appropriate for intended purpose. "3" Seems redundant with other job questions. (E21L)*
- *Again, predicting rather than reporting behaviour. (E25P)*
- *"...Complete it accurately." (E26P)*

Action:

- *Deletion.*

Rationale:

- *Redundant.*

69. If I thought an employer was reluctant to hire a person with a history of a mental illness, I wouldn't apply for the job.

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *"2" (E10, 11A)*
- *Similar to Q63. Do you need both? (E14C)*
- *Again, predicting rather than reporting behaviour. (E25P)*

Action:

- *Deletion.*

Rationale:

- *Redundant.*

70. If I believed that a person I knew thought unfavourably about me because I have a mental illness, I would try to avoid him or her.

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *Q67 covers it. (E10A, 11A)*
- *Same as Q67? (E14C)*
- *Not appropriate for intended purpose. "3" Redundant to Q67. (E20A, 21L)*
- *Again, predicting rather than reporting behaviour. (E25P)*
- *"2" Too similar to Q67. (E26P)*
- *Not appropriate for intended purpose. "3" Redundant to Q67. (E27A)*

Action:

- *Deletion.*

Rationale:
- *Redundant.*

71. **I have claimed to have a different diagnosis so to protect myself from possible rejection.**

❒ Agree ❒ Disagree ❒ Not Sure

Comments:
- *"2" (E7, 11A)*
- *Example of other diagnoses? (E21L)*
- *"2" Do not need "so." (E25P)*
- *"...So as to protect...." (E26P)*

Action:
- *Revision: I have claimed to have a different diagnosis to protect myself from possible rejection.*

Rationale:
- *Grammar.*

72. **When I meet people for the first time, I make a special effort to keep the fact that I have been in psychiatric treatment to myself.**

❒ Agree ❒ Disagree ❒ Not Sure

Comments:
- *Reword? After meeting new people, I eventually share that I have a diagnosed mental illness. (E8A)*
- *"2" Define "special." (E21L)*

Action:
- *Revision: When I am with others I try to hide any visible signs I have because of my mental illness.*

Rationale:
- *Improve clarity.*

73. **I am reluctant to develop new friendships in fear of being rejected because I have a mental illness.**

❒ Agree ❒ Disagree ❒ Not Sure

Comments:
- *"In fear" ("out of fear"/ "for fear?) (E21L)*
- *Not appropriate for intended purpose. "3" Redundant to Q72. (E27A)*

Action:
- *Deletion.*

Rationale:
- *Redundant.*

74. **Individuals who have had a mental illness are able to fit into society.**

❒ Agree ❒ Disagree ❒ Not Sure

Comments:

- *Not appropriate for intended purpose. "3" Suddenly shift from "I." (E21L)*
- *Not appropriate for intended purpose. Not a coping mechanism. (E24P)*
- *Not appropriate for intended purpose. Sounds like you are asking about personal potential rather than societal attitudes. (E25P)*
- *"2" (E27A)*

Action:

- *Deletion.*

Rationale:

- *Not appropriate for intended purpose..*

PLEASE CHECK ONE RESPONSE FOR EACH OF THE FOLLOWING QUESTIONS.

75. What is your current marital status?

- ❒ Single (never married)
- ❒ Common-law
- ❒ Married
- ❒ Separated
- ❒ Divorced
- ❒ Widowed

Comments:

- *"2" (E11A)*
- *Regarding Q75 and Q76: "Common-law" indicates several years of cohabitation. "Partner" (alone) would be better. (E26P)*

Action:

- *Revision: Are you...? Change common-law to "with a partner."*

Rationale:

- *Improve clarity.*

76. Do you live...?

- ❒ Alone
- ❒ With your spouse or common-law partner
- ❒ With your parents or siblings
- ❒ With your spouse or common-law partner and your parents or siblings
- ❒ With others
- ❒ Other Please specify _____

Comments:

- *Point four and five are confusing. Eliminate four; five with roommate. (E6P)*
- *"2" (E11A)*

- *Suggest: 1) alone, 2) spouse/common-law, 3) parents/family, 4) other _____. (E24P)*

Action:

- *Revision: Alone, with your spouse or partner, with your parents or siblings, other.*

Rationale:

- *Improve clarity.*

77. **Do you live in...?**

☐	Your own home	Is your home a...?	☐ House ☐ Condominium
☐	A rented home	Is your home a...?	☐ House ☐ Condominium ☐ Apartment
☐	In your family's (parents or siblings) home Do you share some of the costs?		☐ Yes ☐ No
☐	In your friend's home Do you share some of the costs?		☐ Yes ☐ No
☐	Sheltered accommodation		
☐	Group home		
☐	Other Please specify_____		

Comments:

- *But only main categories (E4P)*
- *Value of this much detail? (E6P)*
- *Ask consumers what terms are meaningful. Substitute sheltered accommodation with supported housing. (E9A)*
- *"2" "Condo" irrelevant in rural communities unless surveying some seniors. (E10A)*
- *"2" (E11A)*
- *Question somewhat lengthy and detailed. (E20A)*
- *Not appropriate for intended use. Seems almost intrusive or at least too detailed. (E21L)*
- *Apartments may also be privately owned "apartment/suite' to cover basement suites. (E23C)*
- *"3" Is too much - why do you need it? (E24P)*
- *Do not need additional "In" for family and friend's home. (E25P)*
- *What is the difference between "group home" and "sheltered accommodation"? What about trailer home? Homeless shelter? (E26P)*
- *Not appropriate for intended purpose. Consider a different term for "sheltered accommodation." (E29P)*

Action:

- *Revision: Do you live in ...?*
  - ☐ *Your own home*
  - ☐ *A rented home*
  - ☐ *In someone else's home rent-free*
  - ☐ *Supported housing*
  - ☐ *Group home*
  - ☐ *Homeless shelter*

Rationale:

- *Simplification.*

78. What is the last grade of elementary or high school you completed?

Grade _____

Comments:

- *Regarding Q78 through Q81: Could one question. 'What is the highest education you achieved?' (E4P)*
- *"2" (E7A, 11A)*
- *"3" (E10A)*
- *Assumes no college graduates? (E21L)*
- *Regarding Q78 through Q81: Couldn't you just ask "how many years of education have you received?" (E26P)*

Action:

- *Revision: What is the highest level of formal education you achieved?*
  - ☐ *Less than high school*
  - ☐ *High school graduate*
  - ☐ *Some post-secondary studies (no degree or diploma)*
  - ☐ *Diploma*
  - ☐ *University degree*
  - ☐ *Post-graduate studies (degree or no degree)*

Rationale:

- *Simplify - combine questions 78 through 81. Delete intrusive questions.*

79. At what age did you complete this grade? _____ Years

Comments:

- *Not appropriate for the intended purpose. "3" (E6P, 10A, 20A, 25P, 26P, 27A)*
- *"2" (E7A, 11A)*
- *Regarding Q79 through Q81: "2" Collapse these into one, shorter question? (E21L)*
- *"2" Ask: Did you fail? Or Did you skip? (E24P)*

Action:
- *Deletion.*

Rationale:
- *Not appropriate for intended purpose.*

80. **Have you attended technical, trade or vocational school?** ❒ Yes ❒ No
If yes, have you received a diploma? ❒ Yes ❒ No

Comments:
- *"2" (E7A, 10A, 11A)*
- *Regarding Q80 and 81: One question! (E24P)*
- *Not appropriate for the intended purpose. "3" (E26P)*

Action:
- *Deletion: Concept covered in plan for Q78.*

81. **Have you attended university?** ❒ Yes ❒ No
If yes, have you received a degree? ❒ Yes ❒ No
If yes, what was the last degree you received? ❒ Bachelor's ❒ Master's ❒ Doctorate's

Comments:
- *"2" (E7A, 10A, 11A, 26P)*

Action:
- *Deletion: Concept covered in plan for Q78.*

82. **Are you currently employed?** ❒ Yes ❒ No

Comments:
- *"2" (E7)*
- *I usually also ask, "Have you worked continuously for the past 3 months" which gives much harder data. (E26P)*

Action:
- *Add question: Have you worked consistently for the past 3 months?*
  ❒ *Yes* ❒ *No*

IF NOT, GO TO QUESTION NUMBER 86.

If yes:

83. **Are you employed ...?**
- ❒ Full-time
- ❒ Part-time
- ❒ Casual (no benefits)
- ❒ Contract

Comments:

- *Self-employed? (E4P)*
- *"2" Add self-employed. (E7A)*
- *"2" (E11A)*
- *Casual? Don't understand. (E21L)*
- *I am not clear what the difference is between casual & part-time & contract. Also, what about previous employment? (E25P)*
- *What is "contract." (E26P)*

Action:

- *Revision: Delete casual. Replace contract with self-employed.*

Rationale:

- *Improve clarity.*

84. What is your job or occupation? _____

_____

Comments:

- *Not appropriate for intended purpose. How will you classify occupation? (E4P)*
- *"2" May be irrelevant? (E5L)*
- *"2" (E7A, 11A, 24P, 26P)*

Action:

- *Deletion.*

Rationale:

- *Not appropriate for intended purpose.*

85. Do you use your education in your present work?

❒ Yes ❒ No

Comments:

- *Not appropriate for the intended purpose. "3" (E4P)*
- *"2" (E10A, 11A, 26P)*
- *Not appropriate for the intended purpose. "3" (E20A, 25P)*
- *Not appropriate for intended use. Can't say I use 10% of mine. (E21L)*
- *Not appropriate for the intended purpose. (E24P)*

Action:

- *Deletion.*

Rationale:

- *Not appropriate for intended purpose.*

86. Are you currently...? (Check as many as apply.)

❒ A homemaker
❒ A student
❒ A volunteer

- ❒ Retired
- ❒ Unable to work because of my mental health problems
- ❒ Unable to work because of other illness
- ❒ Unable to work because of disability from injury

Comments:

- *"2" (E20A, 24P, 26P)*
- *What about people who are unemployed for reasons other than what you've given? (E25P)*
- *Not appropriate for intended purpose. What about involuntary unemployment. (E29P)*

Action:

- *No change.*

87. Do you attend religious services? ❒ Yes ❒ No

Comments:

- *Regarding Q87 through Q89: Not appropriate for intended purpose. Why single out religion? (versus frequency of other social contacts). (E4P)*
- *Regarding Q87 through Q89: Do you have hypothesis around religion and therefore need this detailed account. (E6P)*
- *"2" (E7A, 25P)*
- *Regarding Q87 through Q89: Not appropriate for intended purpose. "3" Purpose of this line of questioning? (E10A)*
- *Regarding Q87 through Q89: Is there a way to collapse these into one? Seems so detailed as to be almost intrusive. (E21L)*
- *"3" Can't you combine Q87 and Q88 by just asking Q88? (E26P)*
- *Regarding Q87 through Q89: Not appropriate for the intended purpose. "3" (E27A)*

Action:

- *Deletion.*

Rationale:

- *Not appropriate for intended purpose.*

If yes:

88. How often do you attend?

- ❒ One or more times per week
- ❒ Less than once a week but more than once a month
- ❒ Once a month or less

Comments:

- *"2" May be inflated. (E5L)*
- *"2" (E7A, 11A, 24P, 25P)*

- *Not appropriate for intended purpose. I wonder if 1 x per week shouldn't be its own response option - that would seem to be a meaningful category i.e., "regular churchgoers" (E29P)*

  Action:
- *Deletion.*

  Rationale:
- *Not appropriate for intended purpose.*

89. Do you consider yourself?

- ☐ Christian
- ☐ Jewish
- ☐ Hindu
- ☐ Muslim
- ☐ Other Please specify_____

Comments:

- *"2" may not be relevant. (E5L)*
- *"2" (E7A, 11A, 24P, 25P)*
- *Add Buddhist. (E9A)*

Action:

- *Deletion.*

Rationale:

- *Not appropriate for intended purpose.*

Additional comments:

Action:

- *Delete statement.*

Rationale:

- *Avoid analysis of qualitative data.*

THANK YOU VERY MUCH FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE!!

PLEASE RETURN IT TO THE INVESTIGATOR

General questions to expert panel:

1. Are there any relevant and important topics that have been omitted from the questionnaire? What are they? Please provide a question if possible?

- *I had two additional areas to suggest inquiring about.*

  **1. Access to general medical care & attitudes of general health care providers. The general health of people with major illness, specifically schizophrenia is worse than the general population and their longevity is*

affected. Health workers were to have been targeted for education in the stigma campaign.

**2. Access to education and the attitude of educators. The onset of these disorders is often during the time people are obtaining their education. (E1)*

- *Are currently receiving care for a mental problem? (E4)*
- *Perhaps a question on positive media? In contrast to balance Q35. (E5)*
- *Could ask if people would remain married to someone with a mental illness. (E7)*
- *Should also ask when first signs were noted - how long to get a diagnosis. (E7)*
- *Should also ask how many diagnoses have been given. (E7)*
- *Questions about fighting for new medications due to cost or lack of physician knowledge. Refused medical attention when requested - told nothing can be done. (E7)*
- *Might want to ask how many different diagnoses people have had. (E8)*
- *Causation of mental illness. Poor parenting is a causative factor for developing schizophrenia? Treatment of mental illness e.g., is appropriate and effective treatment for schizophrenia; (Consumer understanding of mental illness.) What about asking respondents if they think that most people believe that schizophrenia = split personality (very common). (E8)*
- *No. (E9)*
- *Maybe more on mood, affect, etc. ; counselling & its importance(E11A)*
- *I did not notice questions regarding stigma and discrimination within the mental health care system. The stigma encountered in our mental health system usually occurs during the early onset of the illness, which sets the tone for the patients' perception of himself and how the world will receive him for the rest of his life. It is the <u>most</u> damaging of all the stigma and discrimination that exists! It is also far more prevalent than we think it is? (E14C)*
- *Other important questions: Are you an employer? Would you hire someone with schizophrenia or some other mental disorder? If you are a landlord have you ever rejected renting to someone with a mental illness. What have you personally to alleviate the stigma of schizophrenia? Or have you done anything to educate people with schizophrenia. (E19C)*
- *Questionnaire seems very complete. (E20A)*
- *Information relevant to the answers given to participants might flow from a few questions about relationships with: - parents; siblings; friends/acquaintances with a mental illness; friends/acquaintances without a mental illness. (E23C)*
- **Is it reasonable to expect a mentally ill person to work at "full capacity"? What is stigma preventing you from getting?(E24P)*
- *coping mechanisms: you have asked about do not include advocacy - speaking out, challenging, confronting, contributing to organized efforts for change (not just education). Many of our respondents reported that this was important for*

them in overcoming their own sense of stigma and inadequacy. A demographic question about racial/ethnic identity would be useful. (E25P)

- *One concern that I would have would be the utility of the instrument for evaluating efforts to reduce stigma. I think that the draft instrument has some strengths and weaknesses in this regard.*

  1) Your conceptual model suggests that if the subjects' culturally induced expectations of rejection and devaluation change, then stigma would be reduced. So that if you were using the scale (a subscale from this instrument, I expect) to evaluate such expectations, then it could be used to evaluate a program designed to change such expectations (presume by inducing cultural changes, such that consumers perceptions and expectations of acceptance change as a result). If this is the goal of such a public health program, however, it might be more interesting to look at attitudes among the stigmatizers (i.e., the general population) than perceptions of these attitudes (manifested as expectations) among the consumers. That would be a more direct approach.

  2) If the goal of the anti-stigma program was to alter coping mechanisms - then a focus on the consumers would be a necessity - and you seem to have a good measure of three general categories of coping mechanisms, as defined in your model, so this section of the instrument would get at this issue very well (assuming psychometric properties of the coping mechanisms work out - i.e. You'll need to show that there are actually three factors here).

  3) You get at the issue of rejection/acceptance in a variety of settings (family, work) - but your model regards these as being determinants of stigma. If the idea of the anti-stigma intervention was to foster acceptance of the mentally ill among the non-mentally, then assuming you stick with the strategy of asking consumers what their perceptions of the degree of acceptance they experience (the indirect approach, as opposed to evaluating the stigmatizers actual beliefs), you may need to be more specific in some of the questions in order to measure change. E.g., I get turned down for jobs because I have a history of manic depression, so I answer "sometimes" to question 45. Two years later, there has been a program that drastically changes the behaviour of employers, nevertheless I still answer "sometimes" because of what happened two years ago. (E29P)

<u>Action</u>:

- *Addition: General health care providers have been supportive when I revealed I have a mental illness.*
- *Addition: Teachers and instructors have been supportive when I revealed I have a mental illness.*
- *Addition: I have been denied acceptance into school or education programs when I revealed I have a mental illness {352}*
- *Addition: Are you currently receiving care for a mental problem?*

2. Does the questionnaire have an appropriate format?

- *Consider positive versus negative wording of questions introducing bias. (E4)*
- *Yes. I think the approach is fair and respectful and clear. (E5)*
- *Yes. (E7, 9, 19C, 20A, 26P, 27A)*
- *Yes, but vary with a few True/False questions? (E8)*
- *Difficult to follow in some areas but check boxes are nice. What if respondent can't answer some of questions in section1? (E10)*
- *Fairly easy to read. (E11A)*
- *OK. (E23C)*
- *Yes. It seems clear and easy to follow. I am unclear, however, how this instrument would allow you to evaluate anti-stigma interventions. Will this be used in pre and post assessments of specific interventions? If so, some of the items (historical ones will not change) may not be as useful. (E25P)*
- *Yes, very nicely presented (I especially like the arrows for questions to skip). (E29P)*

3. Is the questionnaire an appropriate length? (The time allotted for the completion of the questionnaire is expected to be 30 minutes.)

- *Too long. Too many similar items. (E4)*
- *I think so. (E5)*
- *Too long! (E6)*
- *Yes (E8)*
- *Too long. Will probably require someone to wait with them as they fill it out. (E9)*
- *Far too long! Concentration levels for many will not allow for completion (particularly in community) therefore probability of returned, accurate responses decrease significantly. (E10)*
- *Maybe a bit long. (E11A)*
- *The questionnaire is too long, some questions are almost identical. (E14C)*
- *This is a very long questionnaire. I wonder if many people will take the time/be able to complete all the questions. Perhaps some questions could be worded to combine a number of them into one. (E20A)*
- *OK. (E23C)*
- *Should do a pilot to determine this. Some questions seem unnecessary or redundant. (E24P)*
- *It seems long. I think it may take thoughtful respondents (or perhaps uncertain or cautious ones) longer than 30 minutes. (E25P)*
- *Too long for more seriously ill clients. (E26P)*
- *Probably should have more time. (E27A)*
- *Yes. (E29P)*

4. Additional comments?

- *The questions seemed clear and comprehensible. You appear to have mixed the questions well to avoid a response bias. The range of issues discussed seems relevant. (E1)*
- *I'm not sure what to make of "not sure" answers. (E5)*
- *"Is the question appropriate for the intended purpose?" is a bit unclear. About this - do you mean overall purpose of questionnaire. (E6)*
- *Reason for splitting demographic data (e.g. questions 1 - 13 and 75 -89)? Would suggest putting all at the end. Have them use concentration and attention at the beginning to answer questions you most want answered. (E6)*
- *It is very important with this population to use short concise wording. (E6)*
- *In designing this did you review alternatives to agree, disagree, not sure, for example a graph. (E6)*

●----------●----------●----------●----------●

strongly disagree *strongly agree*

- *Source of income/AISH/employment should be simplified and grouped together. (E6)*
- *I have not marked all questions re: simplifying language. I believe you need to go through each question and try to decrease the number of words. (E6)*
- *Questions are worded for someone with Grade 12 reading level. Will this cause the subjects difficulty? (E7)*
- *CMHA Calgary did a survey on family support and came up with descriptions of housing /accommodation (Q77). It would be interested to see if their definitions in the demographics section were useful. (E9)*
- *The questionnaire seems to assume respondent is in successful treatment when completing - that is, can provide accurate historical information. Plain language is required - a number of areas the wording is academic which many folks won't understand (e.g., description box after question 13). (E10)*
- *Although I thought most questions were relevant and valuable to the survey, most people would find the whole thing much too long. (E14C)*
- *Some of my working comments and some ideas for restructuring the process:*

  -While there is likely to be stigma attached to conditions such mental illness, would you identify those areas where you have experienced the most stigma: Talking to casual acquaintances; Getting a job; Sharing the special needs I have related to working with others; Rooming with someone who does not have a diagnosed problem; Maintaining close friendships; Dating; Prospects for marriage; Living in a group home setting; Etc.

  - In which conditions do you think stigma is most difficult to handle: Family members; Being in hospital; Overhearing people talking about mental illness; Seeing media portrayals that are blatantly unkind.

-What are the most common misconceptions people seem to have about people with schizophrenia: Danger to themselves; Danger to others; Being hospitalized is a sign of weakness.
- Hope this helps. I've tried to use their expertise to provide information without making it seem to be a personal checklist. (E18P)

- *I would be interested in some facts, for instance this many landlords rent to mentally ill. Most families either stick by mentally ill individual or ostracize them. What percentage of employers actually has mentally ill people when they know of the illness. How many people are actually rejected when employers find out about the illness. (E19C)*
- *Some of the quantitative data from questions 7-12 may not be too reliable, particularly for respondents with a long history of treatment. (E23C)*
- *I would suggest placing demographics at the beginning after Q13. (E27A)*
- *1) If this instrument were intended to evaluate interventions to reduce the tendency to devalue/reject mentally ill persons, I'd stick with the consumer perspective, but target the instrument towards non-consumers. These people "own" the problem in a very real sense.*

  2) If the intervention to be evaluated is designed to alter coping, and ultimately adjustment, then I would add to the current focus on coping styles or strategies an experiential element: looking at feelings of rejection, alienation etc. in, say, "the past month" or past six months." One problem with just looking at coping strategies is that different people may successfully employ different ones. Some may deal by avoidance with the same feelings that others deal with by educating others, but it seems to me that it is possible for different strategies to be better for different people. Somehow, I would think that the instrument needs to get at the question: How bad (e.g., alienated, ostracized, ashamed...) does your experience of illness make you feel? How much of your experience of like is characterized by the negative influence of stigma. (E29P)

Appendix E

Questionnaire Draft 2

(Revision: Based Upon Comments of the Expert Committee)

Participant No._____

We appreciate your co-operation in the development of this questionnaire. It is being devised to learn about the social effects of having a mental illness from the viewpoint of persons with a mental illness. This questionnaire will undergo a number of tests to improve the questions and format. Your answers and feedback will help with this revision process. We are aware that the questions ask for personal information; be assured that your name will not be associated with your answers without your written consent to do so.

1. **Are you** ❒ **male** **or** ❒ **female?**

2. **What is your date of birth?** ___19_____ _____ _____
   (year) (month) (day)

3. **Are you currently receiving care for a mental health problem?**
   ❒ Yes ❒ No

4. **What year did you begin psychiatric treatment?** _____19_____

5. **Have you ever stayed in hospital to receive treatment for a mental illness.**
   ❒ Yes ❒ No

IF NO, GO TO THE NEXT SECTION.

If yes:

6. **Did you stay in a ...?**
   - ❒ Mental hospital
   - ❒ Psychiatric ward in a general hospital
   - ❒ Non-psychiatric ward in a general hospital

7. **Were any of these hospitalizations against your will or involuntary?**
   ❒ Yes ❒ No

THE FOLLOWING STATEMENTS DEAL WITH YOUR OPINIONS.

PLEASE MARK WHETHER YOU AGREE OR DISAGREE WITH EACH OF THE FOLLOWING STATEMENTS.

8. **I believe most people would feel afraid to talk to someone who has a mental illness.**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

9. **I think most people would be uncomfortable working with someone who has a mental illness.**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

10. **I believe most people would maintain a friendship with someone who has a mental illness, once they found out about the mental illness.**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

11. **I think most people would feel uncomfortable living with someone who has a mental illness.**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

12. **I think most people would not date someone who has a mental illness.**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

13. **I believe most people would not marry someone who has a mental illness.**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

14. **I think most people believe that entering a hospital for psychiatric care would be a sign of personal failure**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

15. **I think most people would feel ashamed if others knew that someone in their family has a mental illness.**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

16. **I think most people would be against having a group home for 6-8 people who have a mental illness in their neighbourhood.**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

17. **I think most people would believe that a person who has a mental illness is intelligent.**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

18. **I believe most people would disregard the opinions of someone who has a mental illness..**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

19. **I think most employers would pass over the application of someone who has a mental illness in favour of another applicant.**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

20. **I believe most people would not hire someone who has a mental illness to take care of a family member (e.g., child).**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

21. **I believe most people think that a person who has a mental illness is likely to harm others.**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

PLEASE CHECK THE MOST APPROPRIATE RESPONSE.

22. **Within the last 4 months, I have seen news stories on TV or read articles in the newspapers about people who have a mental illness which were hurtful or offensive.**

❒ Never ❒ Seldom ❒ Sometimes ❒ Often

23. **Within the last 4 months, I have heard people say offensive things about people who have a mental illness.**
❒ Never ❒ Seldom ❒ Sometimes ❒ Often

24. **I have been advised by health care professionals to conceal my mental illness to avoid rejection and discrimination.**
❒ Never ❒ Seldom ❒ Sometimes ❒ Often

25. **I have been advised by health care professionals to lower my expectations for accomplishments in life because I have a mental illness.**
❒ Never ❒ Seldom ❒ Sometimes ❒ Often

THE NEXT SET OF STATEMENTS ASK ABOUT THE REACTIONS YOUR RECEIVED WHEN OTHERS LEARNED THAT YOU HAVE A MENTAL ILLNESS.

IF YOU HAVE NEVER BEEN IN THE SITUATION DESCRIBED, PLEASE RESPOND BY MARKING THE BOX "DOES NOT APPLY".

26. **Family members who learned I have a mental illness have been supportive.**
❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

27. **Friends who learned I have a mental illness have been supportive.**
❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

28. **Teachers and instructors have been supportive when I revealed I have a mental illness.**
❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

29. **I have been denied acceptance into school or education programs when I revealed I have a mental illness.**
❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

30. **I have been treated as less competent by others because I have a mental illness.**
❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

31. **I have been shunned or avoided by others because I have a mental illness.**
❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

32. **I have been excluded from volunteer activities because I have a mental illness.**
❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

33. **Co-workers and/or supervisors at work were supportive when I revealed I have a mental illness.**
❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

34. **I have lied on applications (for work, housing, etc.) that asked if I had a mental illness for fear that information would be used against me.**
❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

35. **I have been turned down for employment for which I was qualified when I revealed I have a mental illness.**
❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

36. **I have had difficulty renting a home because I have a mental illness.**
❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

37. **General health care providers have been supportive when I revealed I have a mental illness.**
❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

38. **I have been treated fairly by the nurses and doctors when I used hospital emergency services for my mental illness.**
❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

39. **I have been treated fairly by law enforcement officers when I revealed I have a mental illness.**
❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

40. **My mental illness was used against me in non-criminal disputes (i.e., child custody or divorce proceeding).**
❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

41. **Leaders within my religious community have been helpful when I revealed I have a mental illness.**
❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

PLEASE CHECK THE MOST APPROPRIATE RESPONSE.

42. **I keep my diagnosis of mental illness a secret to prevent rejection.**
❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always

43. **When I am with others, I try to hide any visible signs I have because of my mental illness.**
❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always

44. **I have claimed to have a different diagnosis to protect myself from possible rejection.**
❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always

45. **I try to explain my illness to others to help them understand.**
❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always

46. **I avoid people who have negative opinions about mental illness.**
❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always

PLEASE CHECK ONE RESPONSE FOR EACH OF THE FOLLOWING QUESTIONS

47. Are you...?

- ❒ Single (never married)
- ❒ With a partner
- ❒ Married
- ❒ Separated
- ❒ Divorced
- ❒ Widowed

48. Do you live...?

- ❒ Alone
- ❒ With your spouse or partner
- ❒ With your parents or siblings
- ❒ Other

49. Do you live in...?

- ❒ Your own home
- ❒ A rented home
- ❒ In someone else's home rent-free
- ❒ Supported housing
- ❒ Group home
- ❒ Homeless shelter

50. What is the highest level of formal education you achieved?

- ❒ Less than high school
- ❒ High school graduate
- ❒ Some post-secondary studies (no degree or diploma)
- ❒ Diploma
- ❒ University degree
- ❒ Post-graduate studies (degree or no degree)

51. Are you currently employed? ❒ Yes ❒ No

IF NO, GO TO QUESTION 54.

If yes:

52. Are you employed...?

- ❒ Full-time
- ❒ Part-time
- ❒ Self-employed

53. Have you worked consistently for the past 3 months?

❒ Yes ❒ No

54. Are you currently...? (Check as many as apply.)

- ❒ A homemaker
- ❒ A student
- ❒ A volunteer
- ❒ Retired
- ❒ Unable to work because of my mental health problems
- ❒ Unable to work because of other illness
- ❒ Unable to work because of disability from injury

THANK YOU VERY MUCH FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE!!

PLEASE RETURN IT TO THE INVESTIGATOR

Appendix F

Questionnaire Draft 2
With Comments from Masters Students and Planned Revisions

Participant No._____

Overview:

- *Comments made by the Masters Students were summarized below following the template of the questionnaire.*
- *They were asked to review the questionnaire to ensure that the items:*
  - *included words or terms that were simple, direct, and familiar, to the target population,*
  - *were clear and specific and as short as possible,*
  - *did not contain double negatives,*
  - *were not too demanding and did not assume too much knowledge,*
  - *were not leading, biased or objectionable and were applicable to all respondents, and*
  - *provided an appropriate time referent, response categories that were clear and mutually exclusive, and answers that were not influenced by the response styles.*
- *Lastly they were asked to consider the length and flow of the questionnaire, and whether it included appropriate and clear instructions and skip patterns.*
- *All responses were recorded.*
- *Each Student was assigned a unique alphanumeric code. The letter code, "S" represents a student panellist.*
- *An action plan and rationale for the decision was noted.*

We appreciate your co-operation in the development of this questionnaire. It is being devised to learn about the social effects of having a mental illness from the viewpoint of persons with a mental illness. This questionnaire will undergo a number of tests to improve the questions and format. Your answers and feedback will help with this revision process. We are aware that the questions ask for personal information; be assured that your name will not be associated with your answers without your written consent to do so.

Comments:

- *"Be assured that ..." - What does this mean? For pilot, will names be included on form? (S22)*
- *Suggest you mention that because information is of a personal nature that they don't have to answer a question. (S35)*

Action:

- *Revision: Delete phrase "be assured that."*

Rationale:

- *Simplify. Participants will be advised in the consent process that they can skip questions, discontinue, or postpone their involvement at any time.*

1. Are you ❒ male or ❒ female?

Comments:

- *Add three dots after "Are you." (S11)*

Action:

- *Revision: Add three dots.*

Rationale:

- *Format correction.*

2. What is your date of birth? ____19_____ _____ _____
(year) (month) (day)

Comments:

- *mm/dd/yy format is easier for coding - as well, that's usually how people say their birth date. (S2)*
- *Don't need line before "19". (S2, 11, 22, 24)*
- *Extra line for which I do not understand the purpose. (S4)*
- *Eliminate the line before "19". It's initially confusing (to me)! (S32)*
- *The line in front of "19" suggests you want something in the blank. (S35)*

Action:

- *Revision: Delete line before "19". Change order to month, day, year.*

Rationale:

- *Improve familiarity.*

3. Are you currently receiving care for a mental health problem?
❒ Yes ❒ No

Comments:

- *"Or have you ever received care for..." What if non-compliant or refusing care? (S6)*
- *"Care" is ambiguous. I.e. what type of care - medication? - physicians visits? Etc. (S11)*
- *Have you ever received care for a mental health problem? (S22)*
- *Does "receiving care" need a definition or examples? (S32)*
- *"Currently receiving care" may want to add "(that is a psychiatrist, mental health clinic, family doctor)". Could be interpreted that they were taking prescribed medication although not attending regular appointments. Depends on what you want to know. (S35)*

Action:

- *Revision: Have you ever received care from a psychiatrist, a family doctor, or a professional at a mental health clinic for a mental health problem?*

Rationale:

- *Additional detail to improve accuracy.*

4. **What year did you begin psychiatric treatment? _____19_____**

Comments:

- *Would people have received psychiatric Rx? (S2)*
- *Extra line for which I do not understand the purpose. (S4)*
- *Are individuals who answered "no" to Q3 supposed to skip Q4? (S13)*
- *Would some patients be off and on psychiatric prescriptions. Do you want to know when they first began? Are all individuals with chronic mental disorders on psychiatric Rx (if your questionnaire is to be suited for other populations other than schizophrenia). (S14)*
- *Possibly, switch order with Q4? Assumes all respondents received treatment? (S16)*
- *Don't need line before "19". (S22, 24)*
- *"Treatment for mental illness" psychiatric treatment = psychiatrist. (S30)*
- *Eliminate the line before "19." (S32)*
- *The line in front of "19" suggests you want something in the blank. (S35)*

Action:

- *Revision: If yes: What year did you start receiving this care?*
  19_____

Rationale:

- *Improve wording.*

5. **Have you ever stayed in hospital to receive treatment for a mental illness.**

❒ Yes ❒ No

Comments:

- *Need a question mark? (S4,16)*
- *What about just going to the emergency? (S6)*
- *I wonder if a time frame is necessary to distinguish stays from, say, an emergency visit - include "overnight"? (S15)*
- *"Stayed in hospital" - I think you mean this as an inpatient (overnight) stay. Many psychiatric patients are in day programs which may occur in hospital too. Does this need clarification? (S19)*
- *Do you mean an overnight stay or would you want to include a visit to emergency? (S32)*

Action:

- *Revision: Have you ever stayed in hospital (as an inpatient) to receive care for a mental illness?*

Rationale:

- *Added detail to improve accuracy.*

IF NO, GO TO THE NEXT SECTION.

Comments:

- *Place the No box over the arrow. (S11)*
- *The first, "go to next section" - include "question #8" for absolute clarity? (S15)*
- *I like "If no, Go to question 8" like your transition from Q51. (S16)*
- *Go to Question 8 - it is not clear where next section starts. (S22)*
- *Question #8. (S24)*
- *The directions of what question to proceed to next could be clarified by arrows. See notations on questionnaire. Also, when you say "go to next section" you could indicate that this section begins with question 8. (S31)*
- *I found this a bit ambiguous as each box does not systematically separate sections. It would be clearer stated as "If no, Go to Q# ". (S33)*

Action:

- *Revision: If no, go to question 8.*

Rationale:

- *Clarity.*

If yes:

6. Did you stay in a ...?

- ☐ Mental hospital
- ☐ Psychiatric ward in a general hospital
- ☐ Non-psychiatric ward in a general hospital

Comments:

- *"Mental hospital" may be offensive or cause people to "pass"? (S6)*
- *"Mental hospital is an objectionable term. Try a different term if possible - Psychiatric institution? (S11)*
- *Add (mark all that applies). (S16)*
- *Is there room to add "other." (S37)*

Action:

- *Revision: Add: Psychiatric institution (mental hospital), Other (Please specify)___, and (Check as many as apply.)*

Rationale:

- *Response options not mutually exclusive. Options to provide more information to further assess response options.*

7. **Were any of these hospitalizations against your will or involuntary?**

❒ Yes ❒ No

Comments:

- *"under certificate" not clear if against your will means certified. (S30)*

Action:

- *No change.*

Rationale:

- *Assess during pilot test.*

THE FOLLOWING STATEMENTS DEAL WITH YOUR OPINIONS.

PLEASE MARK WHETHER YOU AGREE OR DISAGREE WITH EACH OF THE FOLLOWING STATEMENTS.

Comments:

- *"Please mark whether ...." Probably not necessary since pretty obvious, but should you include "definitely agree" and "definitely disagree" in the instructions. What is the actual difference between "definitely agree" and "agree"? would it be better to use "agree" and somewhat agree" or strongly agree" and "agree"? (S6)*
- *Don't need "I believe" or "I think" before each statement. They're a given part of the statements and it makes the statements a bit confusing. "Strongly" is more appropriate than definitely. (S24)*

Action:

- *Revision: Please check the most appropriate response and change categories to:*

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

Rationale:

- *Clarity.*

8. **I believe most people would feel afraid to talk to someone who has a mental illness.**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

Comments:

- *"Afraid" - what about other feelings? Apprehensive, uncomfortable? (S11)*
- *"Most people" - are afraid of talking to - "someone", or would feel afraid of talking with ...(S22)*

Action:

- *No change.*

Rationale:

- *Need to maintain similar sentence structure for all questions.*

9. **I think most people would be uncomfortable working with someone who has a mental illness.**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

10. **I believe most people would maintain a friendship with someone who has a mental illness, once they found out about the mental illness.**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

Comments:

- *"Maintain a friendship" - maybe change to "would stay friends with ...". (S2)*
- *Stay friends with rather than "maintain a friendship." (S22)*

Action:

- *Revision: ... stay friends with ...*

Rationale:

- *Simplify wording.*

11. **I think most people would feel uncomfortable living with someone who has a mental illness.**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

Comments:

- *"Living with" - as a partner? - roommate? (S11)*
- *May be difficult to answer appropriately - is the person a family member, someone you have known for a long time ... or ? I think this makes a difference as to how the question would be answered. (S33)*

Action:

- *No change.*

Rationale:

- *Assess during pilot test.*

12. **I think most people would not date someone who has a mental illness.**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

13. **I believe most people would not marry someone who has a mental illness.**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

14. **I think most people believe that entering a hospital for psychiatric care would be a sign of personal failure**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

Comments:

- *"Sign of personal failure" - change to more simple wording e.g., "sign that they had failed." (S2)*
- *Add period at end. (S4, 11, 14, 16)*

Action:

- *Add a period.*

Rationale:

- *Format correction.*

15. **I think most people would feel ashamed if others knew that someone in their family has a mental illness.**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

Comments:

- *Ashamed and/or embarrassed? (S2)*
- *Somewhat wordy - but I can't think of an alternative. (S14)*

Action:

- *No change.*

16. **I think most people would be against having a group home for 6-8 people who have a mental illness in their neighbourhood.**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

Comments:

- *Change to "a group home in their neighbourhood for 6-8 people who have a mental illness". (S2)*
- *"Neighbourhood" ambiguous - on their street, block etc? (S11)*
- *Why do you need to add "for 6-8 people" in this question? (S14)*
- *Is "for 6-8 people" needed? (S22)*
- *Insert "in their neighbourhood" before "for 6-8 people ...." (S24)*

Action:

- *Revision: I think most people would be against having a group home in their neighbourhood for people who have a mental illness.*

Rationale:

- *Simplify sentence and reorganize sentence.*

17. **I think most people would believe that a person who has a mental illness is intelligent.**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

Comments:

- *"...A mental illness" can be "intelligent. (S11)*

Action:

- *Revision: ...could be intelligent.*

Rationale:

- *Improve wording.*

18. **I believe most people would disregard the opinions of someone who has a mental illness..**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

Comments:

- *Delete one period. (S4, 11, 16, 19, 24, 31)*
- *Wonder if "disregard" is sufficiently commonly understood - would "ignore" or "not value" or "not take seriously" work as well or better? (S15)*
- *Ignore instead of "disregard." (S22)*

Action:

- *Revision: Replace disregard with ignore. Delete one period.*

Rationale:

- *Simplify wording and format correction.*

19. **I think most employers would pass over the application of someone who has a mental illness in favour of another applicant.**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

20. **I believe most people would not hire someone who has a mental illness to take care of a family member (e.g., child).**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

Comments:

- *Example of "child" in this question could limit the responses. You may want to give more than one example if you are looking for any family member like a parent etc. (S31)*

Action:

- *Revision: Add elderly parent in parenthesis.*

Rationale:

- *Add detail for improved accuracy.*

21. **I believe most people think that a person who has a mental illness is likely to harm others.**

❒ Definitely Agree ❒ Agree ❒ Disagree ❒ Definitely Disagree

PLEASE CHECK THE MOST APPROPRIATE RESPONSE.

Comments:

- *Regarding Q22-25: Would it be better to use numbers since your classification is open to interpretations? (S6)*
- *Regarding Q22-25: "Seldom" and "sometimes" sound very similar to each other would, never, seldom, quite often, and very often work? Or just never, occasionally, often, as a 3-point scale? (S32)*

Action:

- *Revision: Replace seldom with rarely.*

Rationale:

- *Clarity.*

22. Within the last 4 months, I have seen news stories on TV or read articles in the newspapers about people who have a mental illness which were hurtful or offensive.

❒ Never ❒ Seldom ❒ Sometimes ❒ Often

Comments:

- *Is unclear - do you mean the articles were hurtful or the people who have a mental illness who were described in the article were hurtful? (S4)*
- *Offensive to me? To them? (S11)*
- *Perhaps 4 months is too long a recall period? (S13)*
- *Sentence seems awkward, wonder if "hurtful or offensive" clause could come earlier in question structure? (S15)*
- *Maybe split into two questions? (S24)*
- *The phrase "which were hurtful or offensive" is dangling, I think it could apply to the people, rather than the TV or newspaper articles. How about moving it? Try: ...I have seen hurtful or offensive news stories on TV or articles in the newspaper, about people who have a mental illness. (S32)*
- *Wording of the question; I thought you meant was the illness harmful, then I thought you meant was the person harmful - then I realized you meant the news story - just reword it , I think. (S37)*

Action:

- *Revision: Within the last 4 months, I have seen hurtful or offensive news stories on TV or in the newspaper about people who have a mental illness.*

Rationale:

- *Reorganize sentence to improve flow.*

23. Within the last 4 months, I have heard people say offensive things about people who have a mental illness.

❒ Never ❒ Seldom ❒ Sometimes ❒ Often

Comments:

- *Perhaps 4 months is too long a recall period? (S13)*

Action:

- *No change.*

24. I have been advised by health care professionals to conceal my mental illness to avoid rejection and discrimination.

❒ Never ❒ Seldom ❒ Sometimes ❒ Often

Comments:

- *"Conceal" - "hide". "It has been recommended ..." (S2)*
- *"Health care professionals" - others? family, friends? (S11)*
- *Maybe should be rejection or discrimination, unless you want it to be both. (S32)*
- *"Discrimination" and "rejection" - are they the same thing? Can you ask for both. Discrimination seems to be a big word - do doctors actually use it? (Not that I would know since this isn't my field anyway .... (S37)*

Action:

- *Revision: I have been told by a health care professional to hide my mental illness to avoid rejection.*

Rationale:

- *Simplify wording.*

25. I have been advised by health care professionals to lower my expectations for accomplishments in life because I have a mental illness.

❒ Never ❒ Seldom ❒ Sometimes ❒ Often

Comments:

- *"It has been recommended ..." (S2)*
- *"Health care professionals" - others? family, friends? (S11)*
- *Do you think "lower my expectations & accomplishments in life" mean the same thing to everyone and would be construed the same way by health professionals? (S14)*

Action:

- *Revision: I have been told by health care professionals to lower my personal goals because I have a mental illness.*

Rationale:

- *Simplify wording.*

THE NEXT SET OF STATEMENTS ASK ABOUT THE REACTIONS YOUR RECEIVED WHEN OTHERS LEARNED THAT YOU HAVE A MENTAL ILLNESS.

IF YOU HAVE NEVER BEEN IN THE SITUATION DESCRIBED, PLEASE RESPOND BY MARKING THE BOX "DOES NOT APPLY".

Comments:

- *The explanation for the Q≥26 should be on the same page. Can the Q's 26 - ? not be answered by yes, no or N/A? Easier for a subject to complete - but I see why - in terms of analysis, you would want it this way. (S14)*
- *This box would be better on the next page. Reword: "Described, mark the box "Does not apply." (S22)*
- *The directions for a set of questions would be better placed on the page where these questions begin. (S31)*
- *Should this box be at the top if the next page? (S32)*

Action:

- *Revision: ...described, mark the box "Does Not Apply."*

Rationale:

- *Simplify wording.*

26. Family members who learned I have a mental illness have been supportive.

❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Action:

- *Revision: Replace learned with know.*

Rationale:

- *Simplify wording.*

27. Friends who learned I have a mental illness have been supportive.

❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Action:

- *Revision: Replace learned with know.*

Rationale:

- *Simplify wording.*

28. Teachers and instructors have been supportive when I revealed I have a mental illness.

❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Comments:

- *Told them, instead of revealed. (S22)*

Action:

- *Revision: Teachers or instructors who know I have a mental illness have been supportive. Reverse Q28 and Q29.*

Rationale:

- *Simplify wording and reorganize sentence to improve flow.*

29. **I have been denied acceptance into school or education programs when I revealed I have a mental illness.**

❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Comments:

- *Change wording "I didn't get accepted into ..." (S2))*

Action:

- *Revision: I did not get accepted into a school or an education program because I have a mental illness.*

Rationale:

- *Simplify wording.*

30. **I have been treated as less competent by others because I have a mental illness.**

❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Comments:

- *"Less able to do the job ..." (S2))*

Action:

- *Revision: Once others knew I have a mental illness, I was treated as less able to do a job.*

Rationale:

- *Simplify wording and reorganize sentence to improve flow.*

31. **I have been shunned or avoided by others because I have a mental illness.**

❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Action:

- *Revision: I have been avoided by others because I have a mental illness.*

Rationale:

- *Simplify sentence.*

32. **I have been excluded from volunteer activities because I have a mental illness.**

❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

33. **Co-workers and/or supervisors at work were supportive when I revealed I have a mental illness.**

❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Comments:

- *Co-workers and supervisors may have different expectations and should be separated out. For example, the supervisor may have known about the mental illness, but co-workers may not know. (S2)*

Action:

- *Revision: Supervisors at work were supportive when I told them I have a mental illness.*

Rationale:

- *Double question, delete one subject.*

34. **I have lied on applications (for work, housing, etc.) that asked if I had a mental illness for fear that information would be used against me.**

❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Comments:

- *Insert "the" before information. (S24)*

Action:

- *Revision: I have ...that the information...*

Rationale:

- *Grammar.*

35. **I have been turned down for employment for which I was qualified when I revealed I have a mental illness.**

❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Action:

- *Revision: Replace revealed with disclosed..*

Rationale:

- *Improve wording.*

36. **I have had difficulty renting a home because I have a mental illness.**

❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

37. **General health care providers have been supportive when I revealed I have a mental illness.**

❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Comments:

- *Insert "In general", health ... (S11)*
- *Delete General? (S22)*

Action:

- *Revision: Replace revealed with told them.*

Rationale:

- *Simplify wording and assess during pilot test.*

38. I have been treated fairly by the nurses and doctors when I used hospital emergency services for my mental illness.

❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Comments:

- *"Fairly" is unclear: respectfully? Quickly? (S11)*

Action:

- *No change.*

Rationale:

- *Assess during pilot test.*

39. I have been treated fairly by law enforcement officers when I revealed I have a mental illness.

❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Action:

- *Revision: Replace revealed with told them.*

Rationale:

- *Simplify wording and assess during pilot test.*

40. My mental illness was used against me in non-criminal disputes (i.e., child custody or divorce proceeding).

❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Comments:

- *Used e.g., before in Q20. (S16)*
- *In legal vs. non-criminal. Does it matter if it is criminal or non-criminal? (S22)*
- *Should "i.e., " be "e.g.,". If you mean those to be examples? Or maybe write out "for example" to avoid confusion? (S32)*

Action:

- *Revise: My diagnosis of mental illness was used against me in a non-criminal dispute (e.g., child custody or divorce proceeding).*

Rationale:

- *Improve wording.*

41. Leaders within my religious community have been helpful when I revealed I have a mental illness.

❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Comments:

- *Supportive vs. helpful? (S16)*

Action:

- *Revision: Leaders within my religious community have been supportive when I told them I have a mental illness.*

Rationale:

- *Change wording to improve consistency.*

PLEASE CHECK THE MOST APPROPRIATE RESPONSE.

42. I keep my diagnosis of mental illness a secret to prevent rejection.

❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always

Comments:

- *Similar to Q34. (S16)*
- *Substitute "avoid" for "prevent". (S24)*
- *Q42 and Q44 - redundant? (S30)*
- *Regarding Q42-46: Use of words seldom/sometimes now are a 5-point scale. Would it be better to make all your Likert scales 5 point and adopt the same words? (S32)*

Action:

- *Revision: Replace prevent with avoid.*

Rationale:

- *Improve wording.*

43. When I am with others I try to hide any visible signs I have because of my mental illness.

❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always

Comments:

- *"Visible signs" of what? (S??)*
- *Would the question be smoother if "I have because" is removed from the question? (S15)*
- *Would it be better to just say "... hide any visible signs of my mental illness"? It might be clearer, easier to understand. (S19)*
- *Delete "I have because". (S24)*
- *Had to read it more than once. I think it is the phrasing "visible signs I have" but can't suggest alternative wording. (S35)*
- *"Visible signs" - can you clarify to say "visible signs of the sickness"? (S37)*

Action:

- *Revision: Delete "I have because."*

Rationale:

- *Simplify sentence and assess during pilot test.*

44. I have claimed to have a different diagnosis to protect myself from possible rejection.

❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always

Comments:

- *Wonder if a time frame is beneficial to this question e.g., "In the past I have claimed...". (S15)*
- *Is the "different diagnosis" referring to a mental diagnosis or can it be any diagnosis. (S21)*
- *Insert "mental illness" before "diagnosis.' (S24)*

Action:

- *Revision: I have claimed to have a different diagnosis to avoid rejection.*

Rationale:

- *Simplify sentence.*

45. I try to explain my illness to others to help them understand.

❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always

46. I avoid people who have negative opinions about mental illness.

❒ Never ❒ Seldom ❒ Sometimes ❒ Often ❒ Always

Comments:

- *"Who have" - voice? (S11)*

Action:

- *Revision: I avoid people who have made negative comments about people with a mental illness.*

Rationale:

- *Improve wording.*

PLEASE CHECK ONE RESPONSE FOR EACH OF THE FOLLOWING QUESTIONS

Comments:

- *Curious - why are there demographics type Q at the beginning - then reintroduced at the end. (S14)*

Action:

- *No change.*

Rationale:

- *Demographics were split to ease participants into the questionnaire (easy to answer questions) but to defer some demographics to focus participants quickly into the scale.*

47. Are you...?

- ❒ Single (never married)
- ❒ With a partner
- ❒ Married
- ❒ Separated
- ❒ Divorced
- ❒ Widowed

Comments:

- *Where does common-law fit? Does this [with a partner] include a boyfriend/girlfriend? (S2)*
- *"With a partner" category - assumes unmarried or common law with this partner but person also be separated, divorced, widowed and be "with a partner". i.e., two responses possible. (S19)*
- *Response "with a partner" should probably include something to the effect of (but not married) in parentheses. (S31)*
- *Does "with a partner" mean dating someone? It doesn't seem to relate to marital status unless you mean common law. (S32)*

Action:

- *Revision: Add: "(Check as many as apply.)" and "With a partner (but not married)."*

Rationale:

- *Added detail to improve accuracy and recognize response choices are not mutually exclusive.*

48. Do you live...?

- ❒ Alone
- ❒ With your spouse or partner
- ❒ With your parents or siblings
- ❒ Other

Comments:

- *When "other" is a potential response you should probably allow the individual completing the questionnaire "to describe or specify". It's possible that the respondent may give a response that is equivalent to one of the other response options. (S31)*
- *Do you want them to expand on "other"? (S32)*
- *Do you want to know what "other" is? (S35)*

Action:

- *Revision: Add Please specify to "other" category.*

Rationale:

- *Offer opportunity to specify alternatives to assess response options in pilot test.*

49. Do you live in...?

- ❒ Your own home
- ❒ A rented home
- ❒ In someone else's home rent-free
- ❒ Supported housing
- ❒ Group home
- ❒ Homeless shelter

Comments:

- *A rented home/apartment. Add other option. (S2)*
- *You should probably have an "other" response (see remarks on Q48). (S31)*
- *Where would you put someone who still lived with her/his parents? Own home? Someone else's home free? (S32)*
- *Is there room to add "other". (S37)*

Action:

- *Revision: Add Other (Please specify.)*_____

Rationale:

- *Add "other" option to gather feedback in order to assess response options during the pilot test.*

50. What is the highest level of formal education you achieved?

- ❒ Less than high school
- ❒ High school graduate
- ❒ Some post-secondary studies (no degree or diploma)
- ❒ Diploma
- ❒ University degree
- ❒ Post-graduate studies (degree or no degree)

Comments:

- *Diploma - High school, college? (S11)*
- *Diploma - need to indicate this is post-secondary, not high school. (S19)*
- *"High school" is not a standard level - may be grade 9 or 10. Would suggest using a grade number. (S35)*

Action:

- *Revise:*
  - ❒ *Studies after high school (no degree or diploma)*
  - ❒ *College diploma*
  - ❒ *University studies after receiving one university degree*

Rationale:

- *Add detail to improve accuracy.*

51. Are you currently employed? ❒ Yes ❒ No

IF NO, GO TO QUESTION 54.

Comments:

- *Directions for this question on where to proceed could be clarified. (S31)*

If yes:

52. Are you employed ...?

- ❒ Full-time
- ❒ Part-time
- ❒ Self-employed

Comments:

- *Do you need to know blue collar vs. other collar? (S14)*
- *Do you need the option "casual work"? (S21)*
- *Casual. (S30)*
- *Do you want them to check all that apply? E.g., what if someone is self-employed, part-time? (S32)*
- *Is there room to add "other". (S37)*

Action:

- *Revision: Move the option for self-employment to question 54. Add: Part-time or casual.*

Rationale:

- *Response options not mutually exclusive. Add details to improve accuracy.*

53. Have you worked consistently for the past 3 months?

❒ Yes ❒ No

Comments:

- *FT or PT or as above? Which do you mean? (S2)*
- *Regularly vs. consistently? (S22)*

Action:

- *Revision: Replace "consistently" with "regularly."*

Rationale:

- *Improve wording.*

54. Are you currently ...? (Check as many as apply.)

- ❒ A homemaker
- ❒ A student
- ❒ A volunteer
- ❒ Retired
- ❒ Unable to work because of my mental health problems
- ❒ Unable to work because of other illness
- ❒ Unable to work because of disability from injury

Comments:

- *Add "If no:". (S2)*
- *Delete "my" before mental health. From physical? Injury. (S11)*
- *"Unable to work because of disability from injury" - might consider deleting "from injury", or adding another option - "unable to work because of disability." Some individuals have disabilities (e.g., blindness, deafness, inattention disorders) not r/to injuries, but who probably wouldn't consider themselves in the "because of other illness" category. (S13)*
- *How about simply "Unable to find work but not because of the 3 options you provided. (S14)*
- *Add option "other please describe _____. (S31)*

Action:

- *Revision: Self-employed, A homemaker, A student, A volunteer, Retired, Unable to work because of my mental health problems, Unable to work because of another illness, Unable to work because of physical injury or disability, Unemployed and looking for work, Other (Please specify.)*

Rationale:

- *Add details to improve accuracy. Add other (specify) option to evaluate alternatives during pilot test.*

THANK YOU VERY MUCH FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE!!

PLEASE RETURN IT TO THE INVESTIGATOR

Comments:

- *Study co-ordinator. Investigator seems so intrusive. (S16)*

Action:

- *Revision: Replace investigator with study co-ordinator.*

Rationale:

- *Less likely to be perceived as intrusive.*

Additional comments:

- *The questionnaire is pretty black - i.e. lots on a page. Maybe spread out the questions more and also less bolding. Format suggestion: Tick the appropriate box:*

Question	Never	Seldom	Sometimes	Often
I have been advised ...				

(S2)

- *You may run into problems if one person is thinking about mild depressing vs. severe mental illness or well-controlled schizophrenia. May be difficult to get a person who is symptomatic to answer all 54 questions. Seems like a good questionnaire to me. Arrows are effective for skipping. Instructions are easy to follow. (S6)*
- *Don't like the shadow on the response boxes. (S11)*
- *Good length, easy to read and understand. (S13)*

- *Would it be helpful for the subjects if you had explanations why you are asking certain sections of questions i.e., "This next section asks you questions about..." (S14)*
- *I am a novice at questionnaire review, and have a small amount of interview experience. These comments may be outside the scope of what you were hoping to capture as feedback. However, I thought the questionnaire itself was very well done. I am happy to clarify any of my comments. (S15)*
- *Overall, I think it is excellent - good flow, purpose is clear, questions relevant. The reading level is quite high, and most of my comments relate to simplifying the language of the questions. There are likely quite a few places in which shorter words could be substituted for longer words, and where sentence structure could be simplified. (S22)*
- *Clear, understandable instructions. (S19)*
- *When a section carries over to a new page, it would be helpful if the directions are repeated. The directions for a set of questions would be better placed on the page where these questions begin. Overall, the questionnaire flows well, is a good length and is easy to understand. (S31)*
- *Despite all the little picky details, I think it is a great questionnaire. Almost all the questions were clear and all were interesting? I am really not sure if it is important to have all the scales "parallel" i.e., same # of options, same definitions, but there seems to be some changes between terms used in the 4 and 5-point scales. (I would be interested to know if it matters - let me know). (S32)*
- *For the most part, clear, concise questions, and brief, which is nice. (S33)*
- *In lengthy questionnaires it is beneficial to "remind" participants of what they are answering, for example: "once again, we are interested in your opinions". Great work. You have done a great job in covering a large variety of issues. (S35)*
- *Overall, really well done - how exciting!! They were all very clear and the format (with the areas and boxes) was really neat. (S37)*

Appendix G

Questionnaire Draft 3
(Revision: Based Upon Results of Master Students)

Participant No._____

We appreciate your co-operation in the development of this questionnaire. It is being devised to learn about the social effects of having a mental illness from the viewpoint of persons with a mental illness. This questionnaire will undergo a number of tests to improve the questions and format. Your answers and feedback will help with this revision process. We are aware that the questions ask for personal information; your name will not be associated with your answers without your written consent to do so.

1. **Are you ...** ☐ **male** **or** ☐ **female?**

2. **What is your date of birth?** _____ (month) _____ (day) 19_____ (year)

3. **Have you ever received care from a psychiatrist, a family doctor, or a professional at a mental health clinic for a mental health problem?**
   ☐ Yes ☐ No **IF NO, GO TO QUESTION 5.**

If yes:

4. **What year did you start receiving this care?** 19_____

5. **Have you ever stayed in hospital (as an inpatient) to receive treatment for a mental illness?**
   ☐ Yes ☐ No **IF NO, GO TO QUESTION 8.**

If yes:

6. **Did you stay in a ...?** (Check as many as apply.)
   - ☐ Psychiatric institution (Mental hospital)
   - ☐ Psychiatric ward in a general hospital
   - ☐ Non-psychiatric ward in a general hospital
   - ☐ Other (Please specify.) _____

7. **Were any of these hospitalizations against your will or involuntary?**
   ☐ Yes ☐ No

THE FOLLOWING STATEMENTS DEAL WITH YOUR OPINIONS.

PLEASE CHECK THE MOST APPROPRIATE RESPONSE.

8. **I believe most people would feel afraid to talk to someone who has a mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

9. **I think most people would be uncomfortable working with someone who has a mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

10. **I believe most people would stay friends with someone who has a mental illness, once they found out about the mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

11. **I think most people would feel uncomfortable living with someone who has a mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

12. **I think most people would not date someone who has a mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

13. **I believe most people would not marry someone who has a mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

14. **I think most people believe that entering a hospital for psychiatric care would be a sign of personal failure.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

15. **I think most people would feel ashamed if others knew that someone in their family has a mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

16. **I think most people would be against having a group home in their neighbourhood for people who have a mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

17. **I think most people would believe that a person who has a mental illness could be intelligent.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

18. **I believe most people would ignore the opinions of someone who has a mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

19. **I think most employers would pass over the application of someone who has a mental illness in favour of another applicant.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

20. **I believe most people would not hire someone who has a mental illness to take care of a family member (e.g., child, elderly parent).**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

21. **I believe most people think that a person who has a mental illness is likely to harm others.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

PLEASE CHECK THE MOST APPROPRIATE RESPONSE.

22. **Within the last 4 months, I have seen hurtful or offensive news stories on TV or in the newspaper about people who have a mental illness.**

❒ Never ❒ Rarely ❒ Sometimes ❒ Often

23. **Within the last 4 months, I have heard people say offensive things about people who have a mental illness.**

❒ Never ❒ Rarely ❒ Sometimes ❒ Often

24. **I have been told by a health care professional to hide my mental illness to avoid rejection.**

❒ Never ❒ Rarely ❒ Sometimes ❒ Often

25. **I have been told by health care professionals to lower my personal goals because I have a mental illness.**

❒ Never ❒ Rarely ❒ Sometimes ❒ Often

THE NEXT SET OF STATEMENTS ASK ABOUT THE REACTIONS YOUR RECEIVED WHEN OTHERS LEARNED THAT YOU HAVE A MENTAL ILLNESS.

IF YOU HAVE NEVER BEEN IN THE SITUATION DESCRIBED, PLEASE RESPOND BY MARKING THE BOX "DOES NOT APPLY".

26. **Family members who know I have a mental illness have been supportive.**

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

27. **Friends who know I have a mental illness have been supportive.**

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

28. **I did not get accepted into a school or an education program because I have a mental illness.**

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

29. **Teachers or instructors who know I have a mental illness have been supportive.**

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

30. **Once others knew I have a mental illness I was treated as less able to do a job.**

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

31. **I have been avoided by others because I have a mental illness.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

32. **I have been excluded from volunteer activities because I have a mental illness.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

33. **Supervisors at work were supportive when I told them I have a mental illness.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

34. **I have lied on applications (for work, housing, etc.) that asked if I had a mental illness for fear that the information would be used against me.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

35. **I have been turned down for employment for which I was qualified when I disclosed I have a mental illness.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

36. **I have had difficulty renting a home because I have a mental illness.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

37. **General health care providers have been supportive when I told them I have a mental illness.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

38. **I have been treated fairly by the nurses and doctors when I used hospital emergency services for my mental illness.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

39. **I have been treated fairly by law enforcement officers when I told them I have a mental illness.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

40. **My diagnosis of mental illness was used against me in non-criminal disputes (e.g., child custody or divorce proceeding).**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

41. **Leaders within my religious community have been supportive when I told them I have a mental illness.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

PLEASE CHECK THE MOST APPROPRIATE RESPONSE.

42. **I keep my diagnosis of mental illness a secret to avoid rejection.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always

43. **When I am with others I try to hide any visible signs of my mental illness.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always

44. **I have claimed to have a different diagnosis to avoid rejection.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always

45. **I try to explain my illness to others to help them understand.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always

46. **I avoid people who have made negative comments about people with a mental illness.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always

PLEASE CHECK ONE RESPONSE FOR EACH OF THE FOLLOWING QUESTIONS

47. Are you ...? (Check as many as apply.)

- ☐ Single (never married)
- ☐ With a partner (but not married)
- ☐ Married
- ☐ Separated
- ☐ Divorced
- ☐ Widowed

48. Do you live...?

- ☐ Alone
- ☐ With your spouse or partner
- ☐ With your parents or siblings
- ☐ Other (Please specify.)_____

49. Do you live in...?

- ☐ Your own home
- ☐ A rented home
- ☐ In someone else's home rent-free
- ☐ Supported housing
- ☐ Group home
- ☐ Homeless shelter
- ☐ Other (Please specify.)_____

50. What is the highest level of formal education you achieved?

- ☐ Less than high school
- ☐ High school graduate
- ☐ Studies after high school (no degree or diploma)
- ☐ College diploma
- ☐ University degree
- ☐ University studies after receiving one university degree

51. Are you currently employed?

❒ Yes ❒ No

IF NO, GO TO QUESTION 54.

If yes:

52. Are you employed ...?

❒ Full-time

❒ Part-time or casual

53. Have you worked regularly for the past 3 months?

❒ Yes ❒ No

54. Are you currently ...? (Check as many as apply.)

❒ Self-employed

❒ A homemaker

❒ A student

❒ A volunteer

❒ Retired

❒ Unable to work because of my mental health problems

❒ Unable to work because of another illness

❒ Unable to work because of physical injury or disability

❒ Unemployed and looking for work

❒ Other (Please specify.)_____

THANK YOU VERY MUCH FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE!!

PLEASE RETURN IT TO THE STUDY CO-ORDINATOR.

Appendix H

Diagnostic Standards for Schizophrenia and Schizoform Disorders

The classification of schizophrenia and schizophrenia-like disorders is specified in the ICD-10 (WHO, 1992) and the DSM-IV (American Psychiatric Association, 1994). A comparison of the two classification systems is summarized in Table H1.

Table H1: Classification of Schizophrenia and Schizophrenia-Like Disorders in ICD-10 and DSM-IV (Gelder, Gath, Mayou, & Cowen, 1996)

ICD-10	DSM-IV
Schizophrenia • Paranoid • Hebephrenic • Catatonic • Undifferentiated • Residual • Simple schizophrenia • Post-schizophrenia depression • Other schizophrenia • Unspecified schizophrenia	Schizophrenia • Paranoid • Disorganized • Catatonic • Undifferentiated • Residual
Schizotypical disorder	
Schizoaffective disorder	Schizoaffective disorder
Persistent delusional disorders • Delusional disorder • Other persistent delusional disorders	Delusional disorder
Acute and transient psychotic disorders • Acute polymorphic psychotic disorder • Schizophrenic-like psychotic disorder • Other acute psychotic disorder	Brief psychotic disorder • Schizophreniform disorders
Induced delusional disorder	Shared psychotic disorder
Other non-organic psychotic disorders	
Unspecified non-organic psychosis	Psychotic disorder not otherwise specified

Both classifications distinguish schizophrenic illness, though in DSM-IV more emphasis is laid on the course and functional impairment, while in ICD-10 where prominent signs are given more weight. Both classifications separate out disorders with especially prominent mood disturbance (schizoaffective disorders), and also identify illnesses which meet symptomatic criteria for schizophrenia but have a brief duration of symptomology (brief psychotic disorder and schizoform disorder in DSM-IV and acute and transient psychotic disturbance in ICD-10). In addition, both DSM-IV and ICD-10 distinguish illnesses that centre on relatively enduring non-bizarre delusions without other features of schizophrenia (delusional disorder). The diagnostic criteria for schizophrenia have been reprinted from the ICD-10 and DSM-IV in Tables H2 and H3, respectively.

Table H2: ICD-10 Symptomatic Criteria for Schizophrenia*

The normal requirement for a diagnosis of schizophrenia is that a minimum of one very clear symptom (and usually two or more if less clear-cut) belonging to any one of the groups listed as (a)-(d) below, or symptoms from at least two of the groups referred to as (e)-(h), should have been clearly present for most of the time during a period of one month or more.
a) Thought echo, thought insertion or withdrawal, or thought broadcasting;
b) Delusions of control, influence, or passivity, clearly referred to body or limb movements or specific thoughts, actions, or sensations; delusional perception;
c) Hallucinatory voices giving a running commentary on the patient's behaviour, or discussing the patient among themselves, or other types of hallucinatory voices coming from some part of the body;
d) Persistent delusions of other kinds that are culturally inappropriate and completely impossible, such as religious or political identity or superhuman powers and abilities;
e) Persistent hallucinations in any modality, when accompanied either by fleeting or half-formed delusions without clear affective content, or by persistent over-valued ideas, or when occurring every day for weeks or months on end;
f) Breaks or interpolations in the train of thought, resulting in incoherence or irrelevant speech, or neologisms (new word usage);
g) Catatonic behaviour, such as excitement, posturing, or wavy flexibility, negativism, mutism, and stupor;
h) 'Negative' symptoms such as marked apathy, paucity of speech, and blunting or incongruity of emotional responses, usually resulting in social withdrawal and lowering of social performance; it must be clear that these are not due to depression or to neuroleptic medication;
i) A significant and consistent change in the overall quality of some aspects of personal behaviour, manifest as loss of interest, aimlessness, idleness, a self-absorbed attitude, and social withdrawal.

* (World Health Organization, 1992, pp. 87-88)

Table H3: DSM-IV* Diagnostic Criteria for Schizophrenia

A. Characteristic symptoms: Two (or more) of the following, each present for a significant portion of time during a one-month period (or less if successfully treated) 1. delusions 2. hallucinations 3. disorganized speech (e.g., frequent derailment or incoherence) 4. grossly disorganized or catatonic behaviour 5. negative symptoms, i.e., affective flattening, alogia, or avolition [Note: only one Criterion A symptom is required if delusions are bizarre or hallucinations consist of a voice keeping up a running commentary on the person's behaviour or thoughts, or two or more voices conversing with each other].
B. Social/occupation dysfunction: For a significant portion of the time since the onset of the disturbance, one or more major areas of functioning such as work, interpersonal relations, or self-care are markedly below the level achieved prior to the onset (or when the onset is in childhood or adolescence, failure to achieve expected level of interpersonal, academic, or occupational achievement).
C. Duration: Continuous signs of the disturbance persist for at lest six months. This six-month period must include at least one month of symptoms (or less if successfully treated) that meet criterion A (i.e., active-phase symptoms) and may include periods of prodomal or residual symptoms. During these prodomal or residual periods, the signs of the disturbance may be manifested by only negative symptoms or two or more symptoms listed in Criteria A present in an attenuated form (e.g., odd beliefs, unusual perceptual experiences).
D. Schizoaffective and Mood Disorder exclusion: Schizoaffective Disorder and Mood Disorder with Psychotic Features have been ruled out because either (1) no Major Depressive, Manic, or Mixed Episodes have occurred concurrently with the active-phase symptoms, or (2) if mood episodes have occurred during active-phase symptoms, their total duration has been brief relative to the duration of the active and residual periods.
E. Substance/general medical condition exclusion: The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition.
F. Relationship to a Pervasive Developmental Disorder: If there is a history of Autistic Disorder or another Pervasive Development Disorder, the additional diagnosis of Schizophrenia is made only if prominent delusion or hallucinations are also present for at least one month (or less if successfully treated).

* (American Psychiatric Association, 1994, pp. 285-286)

Appendix I

Preliminary Consent Form
(To be printed on University of Calgary letterhead)

Research Project Title:	**The Development of a Self-Report Scale for the Assessment Of Stigma and Discrimination Experienced by Individuals with Schizophrenia**
Investigators:	**Dr. Edgar Love**, MD, Ph.D. (220-4305) Professor, Department of Community Health Sciences The University of Calgary, 3330 Hospital Dr. N.W., Calgary, T2N 4N1 **Dr. Heather Stuart**, MA, Ph.D. (613-545-6000 ext. 7097) Associate Professor, Department of Community Health & Epidemiology Abramsky Hall, Queen's University, Kingston, Ontario, K7L 3N6 **Dr. Ruth Dickson**, MD, FRCP(C) (219-1611) Chief, Specialized Programs Division, Regional Clinical Department of Psychiatry Associate Professor, Department of Psychiatry, University of Calgary Peter Lougheed Centre, 3500 - 26 Ave. N.E., Calgary, T1Y 6J4 **Helen Roman-Smith**, B.Sc. (220-4299) Masters' Student, The University of Calgary
Sponsors:	**The University of Calgary, The Calgary Regional Health Authority**

The purpose of this study is to develop and evaluate a self-report questionnaire designed to assess stigma and discrimination among individuals diagnosed with and receiving treatment for schizophrenia. The reason for developing this questionnaire is to create a tool capable of evaluating anti-stigma interventions from the viewpoint of persons with schizophrenia.

We are looking for eligible individuals who may be interested in volunteering to participate in the study. Participation involves the completion of a questionnaire, taking approximately 30 minutes; it has no impact on the treatment and/or care that you receive. All patients attending the Psychiatric Day Hospital at the Peter Lougheed Centre and consumers in the Calgary Chapter of the Schizophrenia Society of Alberta, being treated for schizophrenia, are being considered for this study.

If you may be interested in participating in the study, your signature on this form provides permission for a member of the research team to come and speak with you about the study. This meeting will take place at the Peter Lougheed Centre, the office of the Calgary Chapter of the Schizophrenia Society or the Health Sciences Building at the

University of Calgary (Foothill Site) at a mutually convenient time. You will also have the opportunity to ask questions about it. You may then choose to participate, or you may choose not to participate.

If you are not interested in participating in the study, simply do not sign this form.

Name: _____ Date: _____

_____
(Signature)

Please describe how the Research Co-ordinator should contact you to arrange this meeting.

_____

Appendix J

Definitive Consent Form
(To be printed on University of Calgary letterhead)

Research Project Title:	**The Development of a Self-Report Scale for the Assessment Of Stigma and Discrimination Experienced by Individuals with Schizophrenia**
Investigators:	**Dr. Edgar Love**, MD, Ph.D. (220-4305) Professor, Department of Community Health Sciences The University of Calgary, 3330 Hospital Dr. N.W., Calgary, T2N 4N1 **Dr. Heather Stuart**, MA, Ph.D. (613-545-6000 ext. 7097) Associate Professor, Department of Community Health & Epidemiology Abramsky Hall, Queen's University, Kingston, Ontario, K7L 3N6 **Dr. Ruth Dickson**, MD, FRCP(C) (219-1611) Chief, Specialized Programs Division, Regional Clinical Department of Psychiatry, Associate Professor, Department of Psychiatry, University of Calgary Peter Lougheed Centre, 3500 - 26 Ave. N.E., Calgary, T1Y 6J4 **Helen Roman-Smith**, B.Sc. (220-4299) Masters' Student, The University of Calgary
Sponsors:	**The University of Calgary, The Calgary Regional Health Authority**

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

1. The purpose of this study is to develop and evaluate a self-report questionnaire designed to assess stigma and discrimination among individuals diagnosed with and receiving treatment for schizophrenia. The reason for developing this questionnaire is to create a tool capable of evaluating anti-stigma interventions from the viewpoint of persons with schizophrenia.

2. Your participation in this study would involve completing a questionnaire, which will be given and explained to you by the Research Co-ordinator. The questionnaire will take about 30 minutes to complete. You do not have to answer any questions that you

are not comfortable with. You can postpone or discontinue your participation at any time.

3. While you may not gain immediately from your participation, it is hoped that the eventual use of this questionnaire will help to gather information that may guide policy and program decisions that will benefit individuals with schizophrenia in the future.

4. Your participation in the study is entirely voluntary. Your participation or non-participation in this study will in no way affect the treatment and/or the quality of health care you receive. We guarantee that we will not tell anyone whether you decided to participate, or not, or to the extent of your participation.

5. All the information you provide will be kept confidential. None of the answers you will give will be shown to your doctors. Your name will not appear on the questionnaire, the only identifier will be a participant number. Because, if you choose to sign the consent form, your name will appear on it, the consent forms will be kept separate from your questionnaire in a secure file. Your completed questionnaire and consent forms will be destroyed seven years after the study is completed; prior to that, they will be stored in a locked cabinet.

6. There is no cost to yourself in your participation in the study.

7. In the event that you suffer injury as a result of participating in this research, no compensation will be provided for you by the University, the Calgary Regional Health Authority, or the Researchers. You still have all your legal rights. Nothing said here about treatment or compensation in any way alters your right to recover damages.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have, further questions concerning matters related to this research, please contact:

Dr. Ruth Dickson at 219-1611 or
Dr. Edgar Love at 220-4305 or
Helen Roman-Smith at 220-4299

If you have any questions concerning your rights as a possible participant in this research, please contact the Office of Medical Bioethics, Faculty of Medicine, University of Calgary, at 220-7990.

Participant's Signature	Date
Investigator and/or Delegate's Signature	Date
Witness' Signature	Date

A copy of this consent form has been given to you to keep for your records and reference.

Appendix K

Questionnaire Draft 3
With Comments from Pilot Test Subjects and Planned Revisions

Participant No._____

Overview:

- *Comments made by the Subjects of the Pilot Test were summarized below following the template of the questionnaire.*
- *Each Subject was assigned a unique alphanumeric code. The letter code, "C" represents a consumer.*
- *Statements written on questionnaire by respondents are included following the response given for that question or item.*
- *An action plan and rationale for the decision was noted.*

We appreciate your co-operation in the development of this questionnaire. It is being devised to learn about the social effects of having a mental illness from the viewpoint of persons with a mental illness. This questionnaire will undergo a number of tests to improve the questions and format. Your answers and feedback will help with this revision process. We are aware that the questions ask for personal information; your name will not be associated with your answers without your written consent to do so.

1. **Are you ...** ❒ **male** **or** ❒ **female?**

2. **What is your date of birth?** _____ _____ 19_____
   (month) (day) (year)

3. **Have you ever received care from a psychiatrist, a family doctor, or a professional at a mental health clinic for a mental health problem?**

   ❒ Yes ❒ No **IF NO, GO TO QUESTION 5.**

If yes:

4. **What year did you start receiving this care?** 19_____

Comments:

♦ *Question missed three times and one time subject (C17) requested receptionist to find information in her medical chart.*

Plan:

- *Revision: How long have you received care for your mental illness?*

❒ *less than 1 year*
❒ *1-5 years*
❒ *6-10 years*
❒ *more than 10 years*

Rationale:

- *Question too demanding for recall; revise to lessen the detail requested.*

5. Have you ever stayed in hospital (as an inpatient) to receive treatment for a mental illness?

❒ Yes ❒ No **IF NO, GO TO QUESTION 8.**

If yes:

6. Did you stay in a ...? (Check as many as apply.)

❒ Psychiatric institution (Mental hospital)
❒ Psychiatric ward in a general hospital
❒ Non-psychiatric ward in a general hospital
❒ Other (Please specify.) _____

Comments:

- *Other: group home YWCA cluster. (C1)*
- *Intensive care for drug over-dose. (C14)*
- *Rehabilitation centre. (C17)*

7. Were any of these hospitalizations against your will or involuntary?

❒ Yes ❒ No

Comments:

- *All subjects except one (C13) understood the intent of the question. One subject suggested including "under the Mental Health Act" in parenthesis (C9).*

Plan:

- *Revision: Were you ever hospitalized against your will (that is committed under the Mental Health Act)?*

Rationale:

- *Improve the clarity of the question..*

THE FOLLOWING STATEMENTS DEAL WITH YOUR OPINIONS. PLEASE CHECK THE MOST APPROPRIATE RESPONSE.

8. **I believe most people would feel afraid to talk to someone who has a mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

Comments:

- *Strongly agree: Until you get to know the person. (C8)*

9. **I think most people would be uncomfortable working with someone who has a mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

10. **I believe most people would stay friends with someone who has a mental illness, once they found out about the mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

Comments:

- *Somewhat agree: It depends how severe – if severe they would stay distant. (C8)*

11. **I think most people would feel uncomfortable living with someone who has a mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

Comments:

- *When subjects were formulating their response three groups were identified. Some subjects grouped all those people they knew and evaluated them as to whether they would be uncomfortable living with someone who has a mental illness. One subject specified grouping all non-family members (C9). The third grouping was the public (C15).*
- *Somewhat agree: She lives with people with mental illnesses, and doesn't know many people outside mental illness. (C14)*

12. **I think most people would not date someone who has a mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

13. **I believe most people would not marry someone who has a mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

14. **I think most people believe that entering a hospital for psychiatric care would be a sign of personal failure.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

15. **I think most people would feel ashamed if others knew that someone in their family has a mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

16. **I think most people would be against having a group home in their neighbourhood for people who have a mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

17. **I think most people would believe that a person who has a mental illness could be intelligent.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

Comments:

- *Somewhat disagree: Not if severe. (C8)*

18. **I believe most people would ignore the opinions of someone who has a mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

19. **I think most employers would pass over the application of someone who has a mental illness in favour of another applicant.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

20. **I believe most people would not hire someone who has a mental illness to take care of a family member (e.g., child, elderly parent).**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

21. **I believe most people think that a person who has a mental illness is likely to harm others.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

PLEASE CHECK THE MOST APPROPRIATE RESPONSE.

22. **Within the last 4 months, I have seen hurtful or offensive news stories on TV or in the newspaper about people who have a mental illness.**

❒ Never ❒ Rarely ❒ Sometimes ❒ Often

Comments:

- *One subject did not take offence by incorrect messages, but accepted it as the media's or other people's (see below) lack of knowledge in the area. (C9)*

Plan:

- *Revision: Within the last 4 months, I have seen harmful news stories on TV or in the newspaper about people who have a mental illness.*

Rationale:

- *Improve wording.*

23. **Within the last 4 months, I have heard people say offensive things about people who have a mental illness.**

❒ Never ❒ Rarely ❒ Sometimes ❒ Often

Comments:

- *Never: My group is mostly those with mental illness. (C8)*

Plan:

- *Revision: Within the last 4 months, I have heard people say unkind things about people who have a mental illness.*

Rationale:

- *Improve wording.*

24. **I have been told by a health care professional to hide my mental illness to avoid rejection.**

❒ Never ❒ Rarely ❒ Sometimes ❒ Often

25. **I have been told by health care professionals to lower my personal goals because I have a mental illness.**

❒ Never ❒ Rarely ❒ Sometimes ❒ Often

Comments:

- *Missing item: Partly because of the mental illness – my personal goals are already shattered. (C8)*

THE NEXT SET OF STATEMENTS ASK ABOUT THE REACTIONS YOUR RECEIVED WHEN OTHERS LEARNED THAT YOU HAVE A MENTAL ILLNESS.

IF YOU HAVE NEVER BEEN IN THE SITUATION DESCRIBED, PLEASE RESPOND BY MARKING THE BOX "DOES NOT APPLY".

26. Family members who know I have a mental illness have been supportive.

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Comments:

- *Responses should be some, none, etc. (C7)*
- *Does not apply: After coming down with mental illness I left my family and friends. (C8)*
- *Subjects indicated that the responses of parents and siblings could be very different and suggested splitting this item into two.*

Plan:

- *Revision: My parents, who know I have a mental illness, have been supportive.*
- *Addition: My brother(s) and sister(s), who know I have a mental illness, have been supportive.*

Rationale:

- *Improve accuracy.*

27. Friends who know I have a mental illness have been supportive.

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Comments:

- *Often: Friends that are supportive stay friends, other are lost. (C7)*

28. I did not get accepted into a school or an education program because I have a mental illness.

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Comments:

- *Does not apply: I had already finished school. (C8)*

29. Teachers or instructors who know I have a mental illness have been supportive.

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

30. Once others knew I have a mental illness I was treated as less able to do a job.

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Comments:

- *Always: Although I always did a better job. (C1)*

- *Does Not Apply: I haven't been well, energy low, mental problems (stress, concentration) or physically (bad back). (C8)*

31. I have been avoided by others because I have a mental illness.

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Comments:

- *Sometimes: Works both ways – friends seem compassionate and more caring. (C1)*
- *Does not apply: Those I know mostly have mental illness. (C8)*

32. I have been excluded from volunteer activities because I have a mental illness.

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Comments:

- *Often: also serious injury, though, too. (C1)*
- *Never: My nurses have found volunteer work. (C8)*

33. Supervisors at work were supportive when I told them I have a mental illness.

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Comments:

- *Does Not Apply: Has been involved in employment preparation centres that specifically hire people with mental illness (C14). Upon discussion with investigator, it was determined not to include this situation for this question.*

34. I have lied on applications (for work, housing, etc.) that asked if I had a mental illness for fear that the information would be used against me.

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

35. I have been turned down for employment for which I was qualified when I disclosed I have a mental illness.

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Comments:

- *Missing items: Don't know. They gave no reason. (C5)*

36. I have had difficulty renting a home because I have a mental illness.

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Comments:

- *Does not apply: I live in an approved home, found by one of my nurses. (C8)*
- *Wondered whether this included having difficulty renting a home because of financial restriction (C14).*

37. General health care providers have been supportive when I told them I have a mental illness.

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Comments:

- *Sometimes: Very extremely dependent upon the disposition of the physician. (C1)*
- *Always: But seldom use; my providers are almost all in the mental health field. (C8)*
- *All except one subject regarded "general health care providers" to include psychiatrists, psychologists, general practitioners, nurses and associated support staff within and outside the mental health services field.*

Plan:

- *Revision: Non-mental health care providers have been supportive when I told them I have a mental illness.*

Rationale:

- *Want to focus on health care providers outside the mental health field.*

38. I have been treated fairly by the nurses and doctors when I used hospital emergency services for my mental illness.

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Comments:

- *Regarding Q38 and 39: Generally, all subjects agreed that the word "fairly" was a good choice, but that "courteous and polite" could be included in parenthesis.*

39. I have been treated fairly by law enforcement officers when I told them I have a mental illness.

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Comments:

- *Never: Whether transfer on route simply or whatever. Cuff too tight for hours, very often bruised wrists, for moments afterwards circulation was cut off. (C1)*

- *Does Not Apply: Only one. (C8)*

40. **My diagnosis of mental illness was used against me in non-criminal disputes (e.g., child custody or divorce proceeding).**

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Comments:

- *Question modified by the respondent to read "criminal disputes". Responded as "always" but coded as a missing item. (C1)*

41. **Leaders within my religious community have been supportive when I told them I have a mental illness.**

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

Comments:

- *Always: Except for impostor reverend. (C1)*

PLEASE CHECK THE MOST APPROPRIATE RESPONSE.

42. **I keep my diagnosis of mental illness a secret to avoid rejection.**

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always

Comments:

- *One subject commented that different strategies of coping were used for different social groups. This subject hid his mental illness from those associated with sports or other hobbies. The subject suggested dividing item #42 into various scenarios. (C4)*

43. **When I am with others I try to hide any visible signs of my mental illness.**

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always

Comments:

- *Missing item (as well as Q44, Q45, and Q46): Most of the people I know have or care for those with mental illness. (C8)*
- *When respondents were asked what they tried to hide, if they were to "hide any visible signs" of their mental illness, responses ranged considerably. In some cases the subject was "hiding" through total withdrawal or by not sharing their opinions (C13). Others interpreted this phrase as concealing pill taking. One used the following example. He stated that if he lost track of a conversation because he heard voices (hallucination) he would ask to have that part of the conversation repeated without explaining what had happened (C16).*

- *Always: She hides things from her doctor, for example saying that everything is alright when something is actually making her angry, for fear of being returned to hospital. (C14)*

44. I have claimed to have a different diagnosis to avoid rejection.

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always

45. I try to explain my illness to others to help them understand.

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always

46. I avoid people who have made negative comments about people with a mental illness.

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always

Comments:

- *Always: Safety factor to stay away from such individuals. (C1)*

PLEASE CHECK ONE RESPONSE FOR EACH OF THE FOLLOWING QUESTIONS

47. Are you...? (Check as many as apply.)

❒ Single (never married)
❒ With a partner (but not married)
❒ Married
❒ Separated
❒ Divorced
❒ Widowed

48. Do you live...?

❒ Alone
❒ With your spouse or partner
❒ With your parents or siblings
❒ Other (Please specify.)_____

Comments:

- *Other: roommate(s) (C6, 10, 11, 13, 14); approved home with two roommates (C8); friend (C15); two friends who have mental illness (C16)*

Plan:

- *Revision: Do you live...? Alone, with a roommate(s), with your spouse or partner, with your parents or brother(s)/sister(s), other (please specify)*

Rationale:

- *Improve clarity and choice of response options*

49. Do you live in...?

- ❒ Your own home
- ❒ A rented home
- ❒ In someone else's home rent-free
- ❒ Supported housing
- ❒ Group home
- ❒ Homeless shelter
- ❒ Other (Please specify.)_____

Comments:

- *Other: rented basement suite. (C1); apartment (C2, 13); room & board (C8, 12)*
- *Rented home should be rented home or apartment. (C7)*
- *Supported housing is actually rented (C14)*
- *Group home: house no supervision (C16)*
- *Can have subsidized housing that is rented. (C17)*

Plan:

- *Revision: Do you live in...? Your own home, a rented apartment or house, a rented subsidized apartment or house, in someone else's home rent free, in someone else's home paying room & board, group home, homeless shelter, other (please specify).*

Rationale:

- *Improve clarity and choice of response options*

50. What is the highest level of formal education you achieved?

- ❒ Less than high school
- ❒ High school graduate
- ❒ Studies after high school (no degree or diploma)
- ❒ College diploma
- ❒ University degree
- ❒ University studies after receiving one university degree

Comments:

- *Has a college degree (C9)*

Plan:

- *Revision: What is the highest level of formal education you achieved? Less than high school, high school graduate, diploma, degree*

Rationale:

- *Reduce unnecessary categories, and redefine options to improve clarity.*

51. Are you currently employed?

❒ Yes ❒ No

IF NO, GO TO QUESTION 54.

Comments:

Plan:

- *Revision: Are you currently employed at a paying job?*

Rationale:

- *To clarify that the question is focusing on paid employment not volunteer work.*

If yes:

52. Are you employed...?

- ☐ Full-time
- ☐ Part-time or casual

53. Have you worked regularly for the past 3 months?

☐ Yes ☐ No

54. Are you currently...? (Check as many as apply.)

- ☐ Self-employed
- ☐ A homemaker
- ☐ A student
- ☐ A volunteer
- ☐ Retired
- ☐ Unable to work because of my mental health problems
- ☐ Unable to work because of another illness
- ☐ Unable to work because of physical injury or disability
- ☐ Unemployed and looking for work
- ☐ Other (Please specify.)_____

THANK YOU VERY MUCH FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE!!

PLEASE RETURN IT TO THE STUDY CO-ORDINATOR.

Additional Comments:

- *Ask how people feel about people with schizophrenia toady, not 30 years ago. (C3)*
- *One subject indicated that he found meeting people very difficult because one of the first questions asked is "what do you do?" which, he feels starts the cycle of lying and remembering the lies used. (C4)*
- *Ask more specific questions relating to details of relationships. For example: separate parents from siblings. (C6)*
- *One subject also commented that people working and living with mental illness have a wider range of what is considered normal and acceptable behaviour. Often people, who were not accustomed to issue of mental illness, would judge the subject's behaviours as symptoms, as a psychiatrist. People also attributed behaviour inappropriately to the effects of the chemicals in medications. (C6)*

- *One subject noted that the discrimination experienced by those with a mental illness could be reversed in the sense that if you appear to be functioning well, people do not realize you have a disability and need support like AISH, and cannot seek employment. This subject recounted being categorized and demeaned as a "lifer" while in hospital. (C7)*
- *I have personally been spoiled. Because my illness my nurses, etc. have helped me recover to the fullest capacity I can be. [Received help through] approved homes, volunteer, Seroquel Study (new medication). There are some support groups out there: Schizophrenia Society, Creative Living, and Peer Support. (C8)*
- *Add - Do you think I would be treated the same as if I had a physical illness. (C9)*
- *Subject #8 predominantly interacted with others who had a mental illness or mental health care providers. In turn, this isolated her from many situations that could be rejecting. Her choice of social network could represent her reaction to a severe form of stigma based upon the anticipation of rejection. Consequently, her responses for a number of items about discrimination and coping mechanisms were left unanswered. The addition of a question asking the respondents to categorize the interactions will help qualify missing items in these two subscales and add to the description of the respondents.*

Action:

- Addition:

  Who do you mainly interact with?

  - ☐ *other people with a mental illness or mental health care workers*
  - ☐ *people who do not have a mental illness or work in mental health care*
  - ☐ *equal halves of the previous two choices*

Appendix L

Questionnaire Draft 4
(Revision: Based Upon Results of Comments of Pilot Test Subjects)

Participant No._____

We appreciate your co-operation in the development of this questionnaire. It is being devised to learn about the social effects of having a mental illness from the viewpoint of persons with a mental illness. This questionnaire will undergo a number of tests to improve the questions and format. Your answers and feedback will help with this revision process. We are aware that the questions ask for personal information; your name will not be associated with your answers without your written consent to do so.

1. **Are you ...** ❒ **male** **or** ❒ **female?**

2. **What is your date of birth?** _____ (month) _____ (day) 19_____ (year)

3. **Have you ever received care from a psychiatrist, a family doctor, or a professional at a mental health clinic for a mental health problem?**

   ❒ Yes ❒ No **IF NO, GO TO QUESTION 5.**

   If yes:

   4. **How long have you received care for your mental illness?**
      - ❒ Less than 1 year
      - ❒ 1 – 5 years
      - ❒ 6 – 10 years
      - ❒ More than 10 years

5. **Have you ever stayed in hospital (as an inpatient) to receive treatment for a mental illness?**

   ❒ Yes ❒ No **IF NO, GO TO QUESTION 8.**

   If yes:

   6. **Did you stay in a ...?** (Check as many as apply.)
      - ❒ Psychiatric institution (Mental hospital)
      - ❒ Psychiatric ward in a general hospital
      - ❒ Non-psychiatric ward in a general hospital
      - ❒ Other (Please specify.) _____

7. **Were you ever hospitalized against your will (that is committed under the Mental Health Act)?**

❒ Yes ❒ No

THE FOLLOWING STATEMENTS DEAL WITH YOUR OPINIONS.

PLEASE CHECK THE MOST APPROPRIATE RESPONSE.

8. **I believe most people would feel afraid to talk to someone who has a mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

9. **I think most people would be uncomfortable working with someone who has a mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

10. **I believe most people would stay friends with someone who has a mental illness, once they found out about the mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

11. **I think most people would feel uncomfortable living with someone who has a mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

12. **I think most people would not date someone who has a mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

13. **I believe most people would not marry someone who has a mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

14. **I think most people believe that entering a hospital for psychiatric care would be a sign of personal failure.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

15. **I think most people would feel ashamed if others knew that someone in their family has a mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

16. **I think most people would be against having a group home in their neighbourhood for people who have a mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

17. **I think most people would believe that a person who has a mental illness could be intelligent.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

18. **I believe most people would ignore the opinions of someone who has a mental illness.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

19. **I think most employers would pass over the application of someone who has a mental illness in favour of another applicant.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

20. **I believe most people would not hire someone who has a mental illness to take care of a family member (e.g., child, elderly parent).**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

21. **I believe most people think that a person who has a mental illness is likely to harm others.**

❒ Strongly Agree ❒ Somewhat Agree ❒ Somewhat Disagree ❒ Strongly Disagree

PLEASE CHECK THE MOST APPROPRIATE RESPONSE.

22. **Within the last 4 months, I have seen harmful news stories on TV or in the newspaper about people who have a mental illness.**

❒ Never ❒ Rarely ❒ Sometimes ❒ Often

23. **Within the last 4 months, I have heard people say unkind things about people who have a mental illness.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often

24. **I have been told by a health care professional to hide my mental illness to avoid rejection.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often

25. **I have been told by health care professionals to lower my personal goals because I have a mental illness.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often

THE NEXT SET OF STATEMENTS ASK ABOUT THE REACTIONS YOUR RECEIVED WHEN OTHERS LEARNED THAT YOU HAVE A MENTAL ILLNESS.

IF YOU HAVE NEVER BEEN IN THE SITUATION DESCRIBED, PLEASE RESPOND BY MARKING THE BOX "DOES NOT APPLY".

26. **My parents, who know I have a mental illness, have been supportive.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

27. **My brother(s) and sister(s), who know I have a mental illness, have been supportive.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

28. **Friends who know I have a mental illness have been supportive.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

29. **I did not get accepted into a school or an education program because I have a mental illness.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

30. **Teachers or instructors who know I have a mental illness have been supportive.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

31. **Once others knew I have a mental illness I was treated as less able to do a job.**

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

32. **I have been avoided by others because I have a mental illness.**

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

33. **I have been excluded from volunteer activities because I have a mental illness.**

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

34. **Supervisors at work were supportive when I told them I have a mental illness.**

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

35. **I have lied on applications (for work, housing, etc.) that asked if I had a mental illness for fear that the information would be used against me.**

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

36. **I have been turned down for employment for which I was qualified when I disclosed I have a mental illness.**

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

37. **I have had difficulty renting a home because I have a mental illness.**

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

38. **Non-mental health care providers have been supportive when I told them I have a mental illness.**

❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

39. **I have been treated fairly by the nurses and doctors when I used hospital emergency services for my mental illness.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

40. **I have been treated fairly by law enforcement officers when I told them I have a mental illness.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

41. **My diagnosis of mental illness was used against me in non-criminal disputes (e.g., child custody or divorce proceeding).**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

42. **Leaders within my religious community have been supportive when I told them I have a mental illness.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always
❒ Does Not Apply

PLEASE CHECK THE MOST APPROPRIATE RESPONSE.

43. **I keep my diagnosis of mental illness a secret to avoid rejection.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always

44. **When I am with others I try to hide any visible signs of my mental illness.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always

45. **I have claimed to have a different diagnosis to avoid rejection.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always

46. **I try to explain my illness to others to help them understand.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always

47. **I avoid people who have made negative comments about people with a mental illness.**
❒ Never ❒ Rarely ❒ Sometimes ❒ Often ❒ Always

PLEASE CHECK ONE RESPONSE FOR EACH OF THE FOLLOWING QUESTIONS

48. Are you...? (Check as many as apply.)

- ❒ Single (never married)
- ❒ With a partner (but not married)
- ❒ Married
- ❒ Separated
- ❒ Divorced
- ❒ Widowed

49. Do you live...?

- ❒ Alone
- ❒ With a roommate(s)
- ❒ With your spouse or partner
- ❒ With your parents or brother(s)/sister(s)
- ❒ Other (Please specify.)_____

50. Do you live in...?

- ❒ Your own home
- ❒ A rented apartment of house
- ❒ A rented subsidized apartment or house
- ❒ In someone else's home rent-free
- ❒ In someone else's home paying room & board
- ❒ Group home
- ❒ Homeless shelter
- ❒ Other (Please specify.)_____

50. What is the highest level of formal education you achieved?

- ❒ Less than high school
- ❒ High school graduate
- ❒ Diploma
- ❒ Degree

51. Are you currently employed at a paying job?

☐ Yes ☐ No **IF NO, GO TO QUESTION 54.**

If yes:

52. Are you employed...?

☐ Full-time
☐ Part-time or casual

53. Have you worked regularly for the past 3 months?

☐ Yes ☐ No

54. Are you currently...? (Check as many as apply.)

☐ Self-employed
☐ A homemaker
☐ A student
☐ A volunteer
☐ Retired
☐ Unable to work because of my mental health problems
☐ Unable to work because of another illness
☐ Unable to work because of physical injury or disability
☐ Unemployed and looking for work
☐ Other (Please specify.)_____

55. Who do you mainly interact with?

☐ Other people with a mental illness or mental health care workers
☐ People who do not have a mental illness or work in mental health care
☐ Equal halves of the previous two choices

THANK YOU VERY MUCH FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE!!

PLEASE RETURN IT TO THE STUDY CO-ORDINATOR.