

DISAGREEMENT IN THE REPORTING OF DEPRESSIVE SYMPTOMS  
BETWEEN PSYCHOGERIATRIC PATIENTS AND THEIR FAMILY  
INFORMANTS

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## PREFACE

The present study was completed as part of a larger study evaluating outcome measures for depression in older people in mental health services which was conducted by the Psychiatry of Old Age Academic Unit team. Primary researchers were Dr Matthew Croucher and Dr Susan Gee.

As part of the collaborative data collection, I was responsible for liaising with informants nominated by patients. This included telephone or in-person contact, obtaining informed consent to participate in research, and coordinating completion of informant versions of the fifteen-item version of the Geriatric Depression Scale and the Clinically Useful Depression Outcomes Scale.

I also shared responsibilities with Dr Susan Gee for liaising with the psychiatric inpatient ward and day hospital clinical staff, data entry, and depression assessments of 125 older psychogeriatric patients. The assessment included verbal administration of the fifteen-item version of the Geriatric Depression Scale and the Clinically Useful Depression Outcomes Scale.

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## ABSTRACT

The present study investigated discrepancy between reports of depressive symptoms of 36 psychogeriatric patients and their family informants. It also examined factors potentially affecting this discrepancy such as selected characteristics of the patients and their informants, the type of measure assessing depression, and the type of depressive symptoms being assessed. The 15-item Geriatric Depression Scale (GDS-15) and the Clinically Useful Depression Outcome Scale (CUDOS) were completed by the patient, and the informant version of both the GDS-15 and CUDOS were completed by their informant. A sizable discrepancy was found between patient and informant reports of depressive symptomatology; informants reported significantly more symptoms than patients themselves. The discrepancy in reports was greater on the GDS-15 than on the CUDOS. Multiple regression analyses revealed that both patient's gender and type of setting (inpatient vs. day hospital) significantly influenced the discrepancy. The highest kappa agreement was obtained on items related to feelings of worthlessness and life satisfaction on the GDS-15, and suicidal ideation and intent on the CUDOS. The study's strengths and limitations, implications for clinical practice and research, and directions for future research are discussed.

## CHAPTER ONE

### 1. Introduction

Depression is a common and debilitating mental-health problem amongst older people, but challenging to assess. Accurate diagnosis of depression is often complicated by multiple issues, such as coexisting physical and mental problems, cognitive difficulties, and changes resulting from normal ageing. The use of information from friends and family of the older person may be useful in increasing accuracy of depression recognition. However, there are a number of questions about differences between the reports of the individuals and their informants. Several variables, such as older person and informant characteristics, type of questionnaire used, and the type of depressive symptoms present can increase or decrease discrepancy between individual and informant reports of depressive symptomatology. The aims of the present study are to examine the discrepancy between ratings of depressive symptoms made by older people and their informants, and to investigate some of the factors that influence this discrepancy.

#### 1.1 Depression in Older People

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM IV-TR; American Psychiatric Association, 2000), symptoms for Major Depressive Episode (MDE) include depressed or irritable mood; loss of interest or pleasure in usual activities; changes in appetite and weight; disturbed sleep; motor agitation or retardation; fatigue and loss of energy; feelings of worthlessness, self-reproach, or excessive guilt; suicidal thinking and attempts; and difficulty with thinking and concentration. Either depressed mood or loss of interest, accompanied by at least four additional symptoms of MDE, need to be present

during the same two-week period and represent a change from previous functioning (American Psychiatric Association, 2000). Major Depressive Disorder (MDD; referred to in the present study as depression) is characterized by one or more Major Depressive Episode without a history of Manic, Mixed, or Hypomanic Episodes (American Psychiatric Association, 2000).

The average age at onset of depression is in the mid-20s but it may begin at any age. At least 60% of individuals who have had a single depressive episode can be expected to have a second one. Individuals who have suffered from two episodes have a 70% chance of having a third one, and individuals who have had three episodes have a 90% chance of having a fourth (Mattisson, Bogren, Horstmann, Munk-Jorgensen, & Nettelbladt, 2007). Thus, in a substantial number of cases the depression is chronic and recurrent. Accordingly, it has been established that older adults who have experienced depression once are more likely to experience a recurrence of their illness (Reynolds, Frank, Dew, Houck, Miller, Mazumdar, et al., 1999).

The 12-month prevalence of depression among community dwelling older people has been estimated to range from 0.6% to 1.7% (Bruce & McAvay, 1998; Browne Oakley, Wells, & Scott, 2006). The 12-month prevalence of subsyndromal depression (i.e., symptoms of depression that do not meet standard criteria for MDD) is around 25% (Lebowitz et al., 1997). The prevalence of depression is higher in medical and institutional settings than for older people living in the community. The 12-month prevalence in primary care samples is 6% to 8%, in nursing home samples ranges from 5% to 26%, in a sample of elderly home-care patients is 13.5%, and in acutely hospitalized older patients is up to 28% (Bruce & McAvay, 1998; Bruce et al., 2002; Koenig, 1997; Li & Yeates, 2007; Seitz, Purandare, & Conn, 2010). Additionally, both the prevalence and incidence of depression double for people aged 70 – 85 years (Nordhus, 2008).

In late life there are some identified differences in the presentation of symptoms of depression (Blazer, 1994; Kane, Ouslander, & Abrass, 2004). These include a lower prevalence of dysphoria or depressive thoughts, fewer ideational symptoms (such as guilt or suicidal ideation) but more prominent and specific somatic symptoms (constipation, weight loss, and aches), feelings of anxiety, and cognitive dysfunction. Also feelings of decreased self-esteem and worthlessness are more frequently reported in the elderly, and ruminative thinking may be prominent (Lawrence, Davidoff, & Berlow, 2003). Hopelessness about future and thoughts about death may be more normative for older people and are not sufficient to indicate depression in the absence of other symptoms (Burns, Lawlor, & Craig, 2004). Depression presenting primarily with physical symptoms, which has been termed as *masked depression*, is common in the geriatric population (Kane et al., 2004). It has been suggested that the frequency with which somatic complaints predominate in older depressed people suggests that an atypical presentation of depression should be considered among the differential diagnostic assessment of patients presenting only with physical symptoms that cannot be explained on the basis of a non-psychiatric illness (Lawrence et al., 2003).

There is evidence that geriatric depression of any severity often results in several debilitating effects such as negative impact on well-being, increased social and physical disability, and earlier institutionalisation (Beekman, Deeg, Braam, Smit, & Van Tilburg, 1997; Dorenlot, Harboun, Bige, Herard, & Ankiri, 2005). Depression has also been repeatedly linked to excess non-suicide mortality; depressed older individuals, particularly men, have shown a mortality increase of 2-3 times that of general population comparison groups of the same age (Burvill, 1994). Subthreshold depression has been associated with significant functional impairments (Blazer, 2003), risk for future MDD (Chopra et al., 2005), and lack of hope for the future (Adams & Moon, 2009). Also, individuals with dementia who suffer from depression have more frequent hospitalizations, have medical diagnoses in

greater number and severity, receive more psychiatric medications, and have higher pain prevalence than individuals with dementia without a diagnosis of depression (Bartels, Horn, & Smout, 2003). A group of primary care studies in the United States has demonstrated significantly higher health care costs for elderly people diagnosed with depression or subsyndromal depression (Katon, Lin, Russo, & Unutzer, 2003; Unutzer et al., 1997). Livingston and colleagues (Livingstone, Thomas, Graham, Blizard, & Mann, 1990) examined the use of health and social services by community-dwelling older people and discovered that those described as cases of 'probable pervasive depression', in contrast to those that were not, were more likely to have seen their general practitioner in the previous month (48% versus 37%). They were also more likely to have been hospitalized (39% versus 24%), require a district nurse (18% versus 9%), a home help (30% versus 19%), and be more frequent users of local day centre facilities (21% versus 11%) (Livingston et al., 1990). Depressive symptoms have also been associated with a subsequent decline in physical functioning (Bruce, Seeman, Merrill, & Blazer, 1994). Moreover, suicide is common in the geriatric population; older white males have the highest rate of completed suicide – up to six times that of the general population (Lebowitz et al., 1997). Depression has also been recognised as a risk factor for suicide in older adults (Bruce et al., 2004). It is for these reasons that accurate assessment, in order to provide informed treatment of depression in later life, is vital.

## 1.2 Challenges in Assessment of Depression in the Elderly

The adequate and time-efficient assessment and diagnosis of depression in older people is becoming an increasingly important public health issue as the number of individuals aged 65 and older progressively grows. By 2010, around 13% of New Zealand's population will be aged 65 years and over and thereafter the proportion of older people in the population will rise significantly (to 22% by 2013 and 25% by 2051) (Coe, 2003).

Assessment of depression in older adults is complex. Several factors may make depressive symptoms difficult to interpret. Firstly, changes due to ageing, as well as several common medical conditions, can lead to the physical appearance of depression, even if depression is not present (Kane et al., 2004). Also, nonspecific and specific physical symptoms may represent a variety of treatable medical illnesses as well as depression (Kane et al., 2004). For example changes in sleep, appetite, and energy can be hard to distinguish from those due to age, medical illness, or depression. A study by Klerman (1989) found that 75% of older adults in primary care had at least one chronic medical illness that mimicked or shared symptoms of depression. Further complicating the issue, depression often accompanies many medical conditions and can exacerbate symptoms of coexisting physical illness (Kane et al., 2004; Lyness et al., 1996). Any medical condition associated with systemic involvement and metabolic disturbances can have profound effects on mental and affective functioning (Kane et al., 2004). The most common among these are fever, decreased cardiac output, dehydration, electrolyte disturbances, and hypoxia. Systemic diseases, especially malignancies and endocrine disorders, are reportedly associated with symptoms of depression. For example patients with cancer of the pancreas often present with depression accompanied by anorexia and back pain. Among the endocrine disorders, thyroid and parathyroid conditions are most commonly associated with depressive symptoms. Zabora et al. found a prevalence of 36.6% of depressive symptoms among pancreatic cancer patients (Zabora, Brintzenhofesoc, Curbow, Hooker, & Piantadosi, 2001). Hypothyroidism often presents as psychomotor retardation and irritability, and in older patients may also manifest as withdrawal and depressed mood. Hyperparathyroidism, with attendant hypercalcemia, can mimic depression as it often presents as apathy, fatigue, bone pain, and constipation. Cardiovascular and nervous system diseases can precipitate symptoms of depression. It has been reported that the incidence rate of depression following a stroke within the same year is

37.8%, and 25% within the same year after a myocardial infraction (Aben et al., 2003). Brain damage, especially in the frontal lobes, such as tumour and subdural haematomas has also been associated with depression (e.g. Lamar, Charlton, Morris, & Marcus, 2010). Older people with dementia, both Alzheimer's Disease (AD) and vascular dementia, may have prominent symptoms of depression. A review by Castilla-Puentes and Habeych (2010) found an overall prevalence of depressive disorders among patients with dementia of 27.41%. Patients with Parkinson's disease also have a high incidence of depression, which ranges across studies between 7 and 75% (Braam et al., 2010). Depression that develops in response to chronic pain, loss of function and self-esteem, dependence, and the fear of death that accompany physical illness can become severe (Kane et al., 2004). A glossary of some of the medical terms used in the introduction is included in Appendix A.

Cognitive impairment, more frequent among older than among younger adults, presents a further difficulty in the assessment of depressive symptoms (Lawrence et al., 2003). Poor recall, reduced insight, and age-related declines in working memory capacity may interfere in obtaining accurate reports about the presence, severity and duration of symptoms (Knauper & Wittchen, 1994). Moreover, it is also initially difficult to distinguish deficits in cognitive and behavioural functioning that are caused by mood disorders from those due to an early dementing disorder (Nordhus, 2008). It is common that depressed older people who present with cognitive dysfunction (such as impaired memory or concentration) often have dementia-like symptoms without actually having dementia (Blazer, 1999). In these incidences, cognitive deficits are often ameliorated through antidepressant treatment (Zisook & Downs, 1998). Nevertheless, a differential diagnosis can be complicated as recent evidence suggests that depression and cognitive decline in the elderly might be correlated. A study by Jorm (2001) reported that depression, especially late-onset depression, may be a risk factor in the development of dementia. Additionally, a long-term follow up study by Alexopoulos and

colleagues (Alexopoulos, Meyers, Young, Mattis, & Kakuma, 1993) concluded that depressive symptoms may be one of the earliest manifestations of primary degenerative dementia. There are no widely used guidelines that would guarantee a correct diagnosis of these two conditions (Fairchild & Scogin, 2008). However, several researchers have considered how to differentiate between depression and dementia, most noteworthy being the observed differences in memory functioning, and more specifically in the rate of forgetting (Lamberty & Bieliauskas, 1993). Those with depression performed at or close to levels of non-depressed peers whereas those with early dementia performed more poorly. Also, individuals with dementia showed great difficulty in completing a task that required them to organise and learn new material while those with depression performed more poorly than normal subjects, but were able to use material presented to them in an organised manner. From a clinical perspective, it has been recommended that for patients presenting with both depressive symptoms and cognitive disturbances, the diagnosis of a depressive episode should be considered whenever anhedonia, an emphasis on personal failures, feelings of worthlessness, or suicidal ideation are present (Zisook & Downs, 1998). Furthermore, there have been recent suggestions in the treatment literature that depression in the elderly should be considered as both a mood and a cognitive disorder (Walker & Steffens, 2010).

In addition to experiencing more frequent physical health difficulties and cognitive deficits (relative to younger adults), older adults commonly face many adverse life losses: of jobs, money, homes, abilities, hopes, dreams, friends and family (Zisook & Downs, 1998). These losses can underlie fear, demoralization, or loneliness, and in some of the more vulnerable elderly they can contribute to the onset, worsening, or persistence of depression (Zisook & Downs, 1998). It has been shown that many older people as well as their family (and often clinicians) believe that depression is a normal response to those losses associated with aging (Katona, 2000; Unutzer, Katon, Sullivan, & Miranda, 1999). This misconception



exacerbates the problem of accurate assessment of depression in the elderly and subsequently interferes with effective treatment of this debilitating condition (Benek-Higgins, McReynolds, Hogan, & Savickas, 2008).

In summary, several challenges surround the assessment of depression in the elderly. Different depression-like symptoms can represent not only depression, but physical illness, or a combination of both. Cognitive deficits, if present, can affect the accuracy of self-reported presentation as well as overlap with diagnostic symptoms of depression. Misconceptions regarding 'normal' ageing and challenges associated with late life can add further difficulties in recognising depression in the elderly.

### 1.3 Methods of Assessment of Depression in the Elderly

When selecting methods of assessment for use with older people, the clinician is encouraged to consider the goals of the assessment, the length of time for assessment, the availability of other informants, the stamina of the older adults, and the availability of appropriate norms for the age, gender, education, and ethnicity of the patient (Edelstein, Northrop, & MacDonald, 2009). The use of multiple methods is recommended and there is a variety of methods to choose from, including structured or unstructured clinical interview, direct observation, self-report scales, and informant-report measures (Fairchild & Scogin, 2008). All of these methods are used in research and clinical practice. However, only self- and informant-report scales are of relevance to the present study and thus the description below will focus only on them.

#### 1.3.1 Self-report.

Self-report scales are used commonly with older adults and are an important part of the assessment of depression. They are most commonly used as screening instruments and to determine the severity of depressive symptoms. They also allow monitoring of an

individual's symptoms over time and comparisons with normative values from appropriate populations. Self-report depression scales are questionnaires that can either be read to or by the older person. They do so at a symptomatic level with a general assumption that there is a linear relationship between the scores and the severity of depression (Burns et al., 2004). Some of the disadvantages of using self-report measures are the requirements of good vision and adequate reading comprehension (Nordhus, 2008). Deficits in any of these functions can influence the validity and reliability of obtained information. Verbal administration of self-report inventories can to some extent compensate for sensory and/or some of the cognitive deficits (Edelstein et al., 2009). However, the evidence for utility of self-reported depression questionnaires is mixed in regard to cognitively impaired older adults (Edelstein, Kalish, Drozdick, & McKee, 1999). It has been reported in several studies that people with AD routinely underreport their symptoms of depressive symptomatology (e.g. Snow, Kunik, Molinari, Orengo, Doody, Graham et al., 2005). Efforts have been undertaken to determine the point at which self-reports of individuals with AD are no longer considered valid (Perkins, 2007). It has been found that self-reports of people with AD who score  $\geq 9$  on *the Mini Mental Status Examination (MMSE)* were considered to be valid; however, below that level dementia impairment is considered to be too severe to enable reliable self-expression (Logsdon, Gibbons, McCurry, & Teri, 2002). Another disadvantage of self-report measures for detecting depression is their tendency to overestimate presence of MDD in the elderly (Arean, Uncapher, & Satre, 1998). In addition, self-reported screening instruments for depression rarely cover all of the criteria needed for a diagnosis of depression (Edelstein, et al., 2009). Thus, it has been suggested that reliance on total scores, without qualitative appraisal of self-reported responses, can be misleading in a clinical context (Woods, 2008). The use of multiple assessment methods can compensate for some of the limitations of self-report measures noted with elderly individuals.

Whether supported by objective results or not, self-report can often reveal the older person's subjective perception of his or her functioning, which can give a valuable insight into a person's own interpretation of his or her condition (Edelstein et al., 2009). Importantly, self-report depression scales usually require little time and resources to administer and score. Thus, their use as a screening or outcome measure is often effective in primary and secondary care (e.g. Smalbrugge, Jongenelis, Pot, Beekman, & Eefsting, 2008; Watson & Pignone, 2003).

### 1.3.2 Use of informants.

Several authors recommend the involvement of multiple informants in the assessment of mental health of older adults (e.g. Davison, McCabe, & Mellor, 2009; Edelstein et al., 2009; Woods, 2008). Considering the many difficulties associated with assessment of depression in the elderly, obtaining information from family members, caretakers, or other resource people can often be helpful.

The use of informants in assessing depression in the geriatric population can be beneficial for a variety of reasons. A study conducted by McAvey, Bruce, Raue and Brown (2004) found that obtaining informant reports of depression may be a useful method for detecting clinically significant cases of geriatric depression that would otherwise be missed when relying only on patient report. As it was noted by Zisook and Downs (1998), the oldest age group (80 years and older) are especially prone to deny not only DSM-IV mood symptoms of depression, but also many of the standard symptoms such as poor sleep or appetite. Moreover, some of the depressive symptoms have been recognised to be more often identified by the family member or a caretaker than by the older person themselves or by their general practitioner (Burrows, Satlin, Salzman, Nobel, & Lipsitz, 1995; Davison et al., 2009). It has also been noted, that in clinical settings information obtained from a relative or carer may assist in the initial assessment of reluctant or inaccessible older patients (Lewis, Hinchcliffe, Katona, &

Livingstone, 1998). There are some suggestions that the use of informant-rated scales may assist in overcoming some of the problems inherent in the use of self-report measures with older people, such as visual acuity problems or cognitive impairment (Burke et al., 1998; Woods, 2008). In regard to assessment of depression in older people with dementia, several investigators have emphasized the importance of obtaining information from both the person with dementia and his/her informant. Family members were found to be often more aware than cognitively impaired individuals themselves of abnormal shifts in mood (Ballard, Bannister, & Oyebode, 1996). Rubin and colleagues concluded that family informants are essential in diagnosing clinically significant depressive symptoms in individuals with very mild to mild dementia of the Alzheimer type (Rubin, Veiel, Kinscherf, Morris, & Storand, 2001). There is a general agreement in the clinical literature that as the severity of dementia increases, determination of depressive symptoms via self-report scales becomes less reliable and informant measures become necessary (e.g. Burns et al., 2004; Edelstein et al., 2009).

However, assessment information provided by informant, although very valuable, is often not without a bias and cannot be uncritically accepted. Personal characteristics of the informant, especially their own mental and physical health, and informant's knowledge of the older person's behaviour affect the accuracy of their ratings. For example Rosenberg, Mielke, and Lyketsos (2005) examined caregiver's input into assessment of depression in 44 individuals with AD. They found that caregiver depression and sense of burden affected their ratings of AD patients' depressive symptomatology. It has also been noted that in patients with dementia one of the most commonly utilized informants is a spouse. However, often the spouse has significant cognitive, emotional, social, or physical problems that may influence accuracy in reporting (Burke et al., 1998).

Thus, the knowledge of rates of agreement/disagreement between geriatric patients and their informants as well as awareness of several factors that can influence discrepancies

between them can assist in accurate interpretation and informed use of data obtained from informants.

## 1.4 Level of Agreement between Older Person and Informant Reports of Depressive Symptomatology

A modest number of studies have examined level of agreement between older person and informant reports of depressive symptomatology. Bassett, Magaziner, and Hebel (1990) examined the correspondence between 538 community-dwelling older women and their family informants' responses on *Centre for Epidemiological Studies Depression Scale (CES-D)*. The authors found a moderate correlation of .59 between respondent and informant responses. However, when examining informant bias, there were no significant differences between older women and their informants mean scores. Using the same instrument, Magaziner and colleagues (Magaziner, Zimmerman, Gruber-Baldini, Hebel, & Fox, 1997) compared responses of 233 medical outpatients with their family informants. They reported a moderate correlation of .45, fair kappa agreement of .38, and positive bias which suggested that informants were consistently overrating depressive symptoms. However, this bias was statistically significant only when the CES-D was scored as a continuous measure as opposed to dichotomous scoring. In a sample of 355 elderly medical homecare patients, which used the mood section of the *Structured Clinical Interview for DSM-IV (SCID)*, an overall observed agreement was 76% and kappa was .39 (McAvay et al., 2004). The authors also concluded that family informants tended to report more symptoms than the elderly patient; the overall prevalence of major depression was 9% according to both sources, but informants reported more subsyndromal depression than patients, 13% and 8% respectively. Teri and Wagner (1991) investigated the agreement between elderly outpatients with diagnosed AD

and their caregivers using the *Hamilton Rating Scale for Depression (HAM-D)*. They reported a moderate to high correlation of .65 between patients and caregivers total scores on HAM-D, as well as an overall finding that caregivers reported more symptoms of depression than did patients. A validation study of the 30 item collateral version of *the Geriatric Depression Scale (CS-GDS-30)*, which compared self and informant reports of depressive symptoms, found that informants reported 28 of 30 items more frequently than patients, but the sensitivity of patient and informant total GDS-30 scores was nearly identical, .7 and .68 respectively when different cut offs were used (14 and 21 respectively) (Nitcher, Bourke, Roccaforte, & Wengel, 1993). Similarly, a validation study of the CS-GDS-30 administered by telephone, reported that while family and friends reported the same pattern of depressive symptoms as the subject, they reported these symptoms at a higher rate (Burke, Rangwani, Roccaforte, Wengel, & Conely, 1997). Finally, Burke and colleagues (Burke et al., 1998) assessed depressive symptoms using the GDS-30 on a sample of 198 subjects with possible or probable AD and 64 cognitively intact subjects. They also found that, in general, family informants consistently perceived more depressive symptoms than subjects.

In summary, studies which investigated the agreement between target older person self-reports and informant reports of depressive symptomatology, have found moderate correlations ranging from .45 to .65. Thus, there is some evidence supporting the validity of informant reports in assessment of depression in late life. At the same time, studies consistently find that there is a considerable discrepancy between older person and informant reports of depression. Furthermore, some of the studies found that informants have a tendency to report more depressive symptoms than the older individuals themselves.

## 1.5 Factors Affecting Discrepancies between Older Person and Informant Reports of Depressive Symptomatology

The finding that self-rated and informant-rated reports are never perfectly correlated is consistent across multiple constructs, patient populations, and types of raters (Snow, Cook, et al., 2005). Several variables have been found to influence the magnitude of these discrepancies. These include both the patient's and informant's characteristics, the assessment method, and characteristics of the construct being assessed. Patients' demographic characteristics appear to be an important factor; for example, older individuals appear less likely to endorse psychiatric symptomatology than younger elderly individuals (e.g., McAvay et al., 2004). Ratings have also been found to be affected by the informant's overall level of education and by specific knowledge of the assessed construct (Neumann, Araki, & Gutterman, 2000). It has been noted that the more the assessment methods of patients and informants vary, the more discrepancy between their reports might be expected (Snow, Cook, et al., 2005). Finally, it has been found that the more subjective a construct is the larger the discrepancy between self- and informant ratings. Good agreement between self- and informant ratings has been reported for levels of functioning, overall health, less private chronic physical health conditions and symptoms (e.g. skin conditions), and preferences for type of health care setting (Neumann et al., 2000). Moderate agreement was reported for estimates of cognitive status, whereas moderate to low agreement has been found for depressive symptoms, psychological well-being, quality of life, and pain (Neumann et al., 2000).

The factors that affect the magnitude of discrepancies between older individuals and his/her informant reports of depressive symptoms are not that well understood. A few studies examined the role of such variables as patient's medical comorbidity, activities of daily living

disability, and cognitive functioning; informant's age and type of relationship to the older person; a form of questionnaire used; or type of depressive symptoms present. These studies are discussed below in more detail.

#### 1.5.1 Patient characteristics.

The previously mentioned study by McAvay et al. (2004) examined associations between patterns of agreement/disagreement and patient and their family informant characteristics. They found that the patient's medical comorbidity and activities of daily living disability levels were associated with discrepancies in family informant's and older person's reports of depression. More specifically, patients with higher medical comorbidity and disability were more likely to underreport depressive symptoms. Using the same sample, McAvay, Raue, Brown, and Bruce (2005) found an overall trend that for patients with cognitive impairment, informants were more likely to report more psychological symptoms than they did for cognitively intact patients. This discrepancy was explained by the fact that cognitively intact patients were more likely to report suicidal thoughts or ideation as opposed to cognitively impaired patients who were less likely to report these symptoms. In both studies (McAvay et al., 2004; McAvay et al., 2005), there was a 40% refusal rate among sampled patients; those who refused to participate were more likely to be female, unmarried, living alone, and without children. Considering a high refusal rate, there is a possibility results were affected by non-participation bias.

Burke et al. (1998) implicated the role of insight in explaining the discrepancy in reporting depressive symptoms by older people with AD and their family informants. Participants with AD who had partial or no insight reported significantly fewer depressive symptoms than those who were cognitively intact. At the same time, those AD participants with full insight reported essentially the same number of symptoms as cognitively intact participants. Thus, lower level of insight increased the discrepancy between the older person and their informant



reports of depressive symptoms. This effect was observed for participants with AD but not for cognitively intact ones. One of the limitations of the Burke et al. (1998) study was that the insight variable was a post-hoc creation using three of the GDS items that relate to memory and concentration. By doing so a concept of insight was restricted to only awareness of cognitive deficits, which puts the generalizability of findings into question.

Cacchione et al. (2003) examined the reporting accuracy of family informants regarding cognitive capabilities of 515 individuals with very mild to mild AD (Cacchione, Powlishta, Grant, Buckles, & Morris, 2003). Characteristics of the elderly individuals with AD that related to greater accuracy of the informant were being male, younger, and more educated. Also, using a sample of male dementia patients Ross et al. (1997) found that older age and lower level of education were positively associated with inaccuracy of informant reports of older patients cognitive functioning. Although these studies did not examine the accuracy in reporting depressive symptomatology, they were carried out in a sample of elderly patients and some of the assessed symptoms overlapped with cognitive symptoms of depression (e.g., memory difficulties and concentration).

Overall, there are not many studies that have examined the role of specific older adults' characteristics in affecting the discrepancy between older person and informant reports of depressive symptomatology. There is some evidence in support of the conclusion that greater medical comorbidity and activities of daily living disability as well as decreased insight may increase discrepancy between older individual and informant reports of depression symptomatology. There is also, from studies assessing cognitive functioning, some support for such demographic factors as patient's older age and male gender widening the gap between older individual and informant reports.

### 1.5.2 Informant characteristics.

In the study by McAvay et al. (2005), younger informants, as compared to older ones, were found to have a significantly higher tendency to report more cognitive and psychological symptoms of depression than the patient. The authors concluded that the patterns of these discrepancies may in part reflect age- and cohort-related differences in concepts about normal cognitive and affective functioning. Similarly, Bassett et al. (1990) found that older informants reported fewer total depressive symptoms compared with younger informants.

The majority of studies in the area of interest did not examine informant's gender or other demographic characteristics apart from age. There is some modest evidence for informant's gender and type of relationship to the older person affecting the agreement between the older person and informant reports of depression. Bassett et al. (1990) found that husbands significantly underestimated the presence of depressive symptomatology in comparison with the number of symptoms endorsed by their wives. Additionally, daughters provided less biased estimates of their mothers' reports of depressive symptoms than other types of informants. It is worth noting that the target sample used in the study comprised entirely of white women over the age of 65, who were generally healthy and lived in the urban community, thus generalizability of the findings might be limited and applicable only to similar samples.

In addition, Cacchione et al. (2003) found that spousal relationship, living with the individual with AD, and seeing the individual frequently increased the accuracy of informants' reports. Conversely, in a study by Burke et al. (1998) the relationship of the informant to the subject did not significantly affect discrepancy between their reports of depressive symptoms.

On the whole, there is some sparse evidence implicating the informant's age and gender as factors that affect the discordant ratings of depression symptomatology. Specifically, the discrepancy in reports might be higher for male informants, and also for those who are younger. Studies that examined the informant's relationship to the older person provide mixed results in terms of its role in having an effect on agreement between informant and older individual ratings of depression symptoms.

### 1.5.3 Measure characteristics.

There is some suggestion in the literature that the type of questions used in questionnaires assessing symptoms of depression in the elderly and the consequent method used to score these questionnaires can influence response agreement and bias. Magaziner et al. (1997) observed less discordance between older person and informant reports of social functioning on questions which were relatively global and which asked simply about participation (i.e., dichotomous yes/no response options) than on questions asking about quantity of participation (i.e., continuous response options). Although, an overall agreement on reports of depressive symptoms was higher using the continuous response options, the use of impaired/unimpaired dichotomy was less likely to result in a biased estimate of impairment. Meaning that when patients' ratings of depressive symptoms were used as a gold standard, using a dichotomous response option resulted in less discrepancy between patient and informant ratings of depressive symptoms than when continuous response options were used.

### 1.5.4 Type of presenting symptoms.

McDade-Montez, Watson, O'Hara, and Denburg (2008) examined the influence of the *visibility effect* on the ease of rating depression and anxiety symptoms by 53 family and 65 staff (professional caregivers) informants of cognitively impaired patients. The visibility effect was described as “...*more easily observed characteristics generally evidence greater agreement between raters*” (McDade-Montez et al., 2008, p. 940). All participants were

given a version of the *Inventory of Depression and Anxiety (IDAS)*, which consisted of 11 standard symptom scales; 174 items altogether. They were instructed to rate each item on a 4-point scale ranging from 1 = *very difficult to rate*, to 4 = *very easy to rate*. The authors found that those symptoms of depression and anxiety that had more obvious external manifestations were easier for family and staff informants to rate, including appetite loss, lassitude, insomnia, and ill temper. Additionally, the more cognitive or emotional symptoms, such as suicidality and traumatic intrusions, were the most difficult for both family and staff members to rate. Appetite gain, social anxiety, well-being, and panic were intermediated in their ratability in both groups. There was a moderate correlation (.66) between the mean item ratability in two groups, suggesting that family members and staff members showed a strong level of agreement about which items were easier versus harder to rate. This supported the argument that certain types of depressive symptoms might be consistently easier to rate for informants, which in consequence would increase agreement between informant and patient ratings. One of the limitations of the study is that the actual informant ratings and parallel patient ratings were not obtained so there was no actual comparison between these two sources of information.

McAvay et al. (2005) examined agreement between patient and informant reports according to type of depressive symptoms. In contrast to what they had hypothesised, observed agreement (51%) was poor and kappa agreement was only fair (.31) for somatic symptoms reports. Additionally, disagreements on the number of somatic symptoms did not follow a systematic pattern. A proposed reason for these unexpected results, was that differences in the type of individual somatic symptoms reported by patients and informants contributed to the overall disagreement. It was supported by the fact that patients were more likely to report sleeping problems, whereas informants were more likely to report fatigue. Observed agreement was higher (75%) and kappa agreement moderate (.41) for

psychological symptoms of depression. Also disagreements on psychological symptoms followed an asymmetric pattern; the probability of the informant reporting one more psychological symptom was 1.4 times that of the patient reporting an additional symptom and 1.8 times reporting two symptoms. For cognitive symptoms observed agreement was also higher (82%), but kappa indicated only very slight agreement (.09). A pattern of disagreement was that informants were 1.7 times more likely to report an additional cognitive symptom than the patient. They hypothesised that the patients might not have been aware of symptoms such as indecisiveness, or ability to concentrate whereas informants were more likely to notice and report these symptoms. Finally, observed agreement was highest (90%) and kappa agreement was moderate (.41) for suicidal symptoms. The pattern of disagreement was reversed for suicidal items; patients were .52 times more likely to report them than informants. The authors suggested that it might have been due to the patient's being more reluctant to mention these types of thoughts to their children, spouses, or friends.

Teri and Wagner (1991) also found that certain depressive symptoms were more likely to be viewed differently among sources. For a depressed AD sample, patients endorsed significantly less often than family caregivers (mostly daughters and spouses) such symptoms as insomnia, change in interests, suicidal feelings, and somatic anxiety. Importantly, those four symptoms as well as initial insomnia and loss of insight, were found to best distinguish depressed from non-depressed patients in a discriminant function analysis using clinician ratings. Further understanding of the role of insight in the assessment of depression for people with dementia would be useful, but the implications for assessment with cognitively-intact older people are not clear.

Davison et al. (2009) investigated the effect of including a staff informant interview on prevalence estimations of MDD in a sample of 168 residents of an aged-care facility. The results of an individual clinical interview for MDD were compared with those obtained when

a staff informant interview was incorporated into the assessment, and then both were compared with scores on the GDS-15. They identified a subsample of residents who, although recognised as depressed by the clinician and the informant, failed to disclose depressive symptoms in the clinical interview and endorsed a significantly lower number of items on the GDS-15. The symptom most commonly omitted in clinical interviews was depressed mood. Also other symptoms were commonly denied by those residents, including diminished interest or pleasure in activities, appetite disturbance or weight loss, lack of energy, worthlessness, and suicidal ideation. Thus, it is plausible to presume that agreement between older person and informant reports of the above depressive symptoms would be low. The authors suggested that the underreporting of these symptoms may reflect concern among older people about the stigma of mental illness, lack of insight into their mood, a tendency to normalize depressed mood, or reluctance to disclose affective symptoms. Noteworthy, the majority of the diagnostic interviews with older individuals and staff informants were conducted by a single clinician, thus the information obtained from both sources might not have been entirely independent. Also, the extent to which the study findings would apply to family informants is unclear.

In general, several studies have explored potential effects of the type of depressive symptoms present on agreement between older person and informant reports of depressive symptomatology. Symptoms with obvious behavioural manifestations have been found to be easier to rate for informants, which could subsequently decrease disagreement on reports of these symptoms. However, not all of the studies supported this hypothesis. Depressive symptoms such as insomnia, changes in interests, and suicidal feelings were found to be more likely viewed differently by the older individual and his/her informant. In addition some symptoms, depressed mood in particular, were observed to be consistently underreported by some elderly individuals with depression.

## 1.6 Present Study

The purpose of the present study was to further the understanding of discrepancies between self-reports by older patients and reports by members of their family of depressive symptoms in the older patient. Specifically, the present study examined relationship between ratings of depressive symptomatology made by the older people themselves and those made by their family informant as well as investigating some of the factors that influence this discrepancy. The study sample was comprised of non-demented secondary mental health care patients and their informants (family and friends) who were selected by the patients. Guided by the existing research it was hypothesised that:

1. Informants would report significantly more depressive symptoms than patients.
2. The overall discrepancy between patient's and informant's ratings would be lower on a measure asking about presence/absence of depressive symptoms (GDS-15) than on a measure asking about frequency of these symptoms (CUDOS).
3. Discrepancy between patient's and informant's reports of depressive symptoms would be positively correlated with patient's physical frailty, psychiatric comorbidity, and older age.
4. Discrepancy between patient and informant reports of depressive symptoms would be higher for male and non-partner informants.
5. Finally, it was expected that rates of agreement would be higher on items that refer to symptoms more easily observable with clear behavioural manifestation (e.g., changes in appetite, sleep patterns and energy levels) than on items that referred to intrapsychic symptoms (e.g. feelings of guilt and worthlessness).





## CHAPTER TWO

### 2. Methods

#### 2.1 Participants

Study participants were recruited (1) from a one year cohort of patients admitted to the Older Persons Mental Health “Functional Disorders” Inpatient Unit (hereafter referred to as Ward K2 or inpatient unit) and (2) from a seven-month cohort of patients admitted to a day-hospital - the Mabel Howard Clinic (hereafter referred to as MHC or day-hospital), both Canterbury District Health Board services located in Christchurch, New Zealand. All admitted patients received written information about the study (Appendix B), but were asked to participate only if they were able to give an informed consent in terms of cognitive capacity to understand the research project and potential ability to complete depression questionnaires (as judged by the patients’ primary nurse, the researcher, and the Ward K2 charge nurse or the MHC clinical director). There were no other exclusion criteria. Physically compromised patients who were able to communicate were included in the study. All patients who were selected to participate in the study were given a verbal description of the study and an opportunity to discuss or ask any questions regarding their participation. Patients who consented were asked to select an informant (e.g., a family member or a close friend) and for permission to contact him/her. The appointed informants were phoned by the researcher and included in the study if they consented. No exclusion criteria applied to patients’ informants.

#### 2.2 Setting

The sites for the research - the inpatient psychiatric ward for older people (Ward K2) and a psychiatric day-hospital for older people - were both located at the Princess Margaret

Hospital (PMH) in suburban Christchurch. Both services are part of the Psychiatry Service for the Elderly which is the sole secondary care provider of psychogeriatric services for the Canterbury region of New Zealand. Referrals are received from all primary and secondary care sources in Canterbury and the service acts as a tertiary provider for some out-of-area referrals. A minimum age for the ability to utilize these services is sixty-five years.

Ward K2 provides acute admission, assessment and treatment for ‘functional’ psychiatric disorders such as depression, bipolar disorder, and schizophrenia. Analysis of the previous two years of admissions (2008 & 2009) revealed that the ward has approximately 150 admissions each year. Approximately two-thirds of admitted patients had clinically significant depressive symptoms. The average length of stay on the ward was 38 days.

The Mabel Howard Clinic is a psychogeriatric day-hospital which provides assessment, treatment and rehabilitation programmes. Analysis of the previous two years of admissions (2008 & 2009) revealed that the MHC had approximately 120 admissions each year. At least three quarters of admitted patients had clinically significant depressive symptoms. Clients typically attend weekly. The average participation in services at the MHC day-hospital was 29.5 weeks.

## 2.3 Measures

Demographic and personal information regarding the patients was obtained from each patient’s health file. This included the patient’s age, gender, ethnicity, and contact details for any appointed informant. Patients completed the 15-item *Geriatric Depression Scale (GDS-15)* and the *Clinically Useful Depression Outcome Scale (CUDOS)*. The informant rated the same measures, but making the rating about the patient rather than themselves. Both measures are available in the public domain. The *Health of the Nation Outcome Scales 65+ (HoNOS 65+)* is routinely completed by the attending clinician as a part of standard care in

both the Ward K2 and the MHC. The details of HoNOS 65+ for each patient were extracted from their health file. All of the measures employed in this study are described below in more detail.

### 2.3.1 Geriatric Depression Scale 15- item version.

The GDS-15 (Sheikh & Yesavage, 1986; Appendix C) is a 15-item self-report scale that assesses the presence of depressive symptoms. Respondents are asked to choose the items that applied to them over the period of the past week and responses are provided in a yes/no form. The GDS-15 can be administered orally or in a written format (Parmelee & Katz, 1990). An overall score is obtained by reverse-scoring items 1, 5, 7, 11, and 13, and then summing all responses. A total score ranges from 0 to 15. A recommended cut-off score in older medical inpatients, which is likely to differentiate between non-depressed and depressed patients, is 7 (Cullum, Tucker, Todd, & Brayne, 2006). The GDS-15 has sound psychometric properties, with moderate internal consistency/reliability of .75 (Cronbach's alpha) (Friedman, Marnin, & Delavan, 2005); and, in terms of criterion validity, at the cut-off score of 7 the sensitivity was 70.2% and the specificity was 84.2%. Nyunt and colleagues reported test-retest reliability over two weeks at .83 and inter-rater reliability at .94 (Nyunt, Fones, Niti, & Ng, 2009).

The GDS-15 is a short form of the GDS-30 (Yesavage et al., 1983). The GDS-30 was designed specifically for use with older people by excluding items assessing somatic and vegetative symptoms of depression and adopting a simple yes/no response format. As a screening instrument the GDS-30 is widely used in clinical and research settings. The reliability of the GDS-30 has been found to be high; an average of .84 across a range of studies (Keiffer & Reeses, 2002) and the concurrent validity of the GDS-30 is also high (e.g. Olin, Schneider, Eaton, Zemansky, & Pollock 1992). The correlation between the GDS-30

and the GDS-15 is .84 (Sheikh & Yesavage, 1986); therefore, in the present study the GDS-15 was chosen as a briefer and less time engaging alternative to the GDS-30.

### 2.3.2 Informant version of the GDS-15 (GDSI-15).

The GDSI-15 (Brown & Schinka, 2005, Appendix D) is a version of the GDS-15 but designed for completion by an informant, i.e., person who knows the individual being assessed well enough to act as an informant about their health and well-being. The GDSI-15 has the same item content (with a change of pronoun from 'I' to 'he/she'), format of responses and scoring principles as the GDS-15. A validation study by Brown and Shinka (2005) found the GDSI-15 to have sufficient internal consistency/reliability (Cronbach's  $\alpha = .86$ ) and retest reliability ( $r = .81$ ), as well as good construct validity.

### 2.3.3 Clinically Useful Depression Outcome Scale.

The CUDOS (Zimmerman, Chelminsky, McGlinchey, & Posternak, 2008; Appendix E) is an 18-item scale which measures depression across the respondent's past week. The sixteen items assess the DSM-IV symptom criteria (for criteria with more than one construct, the subcomponents are assessed in separate questions) and two further items assess global perception of psychosocial impairment due to depression and overall quality of life. Answers are rated on a 5-point (0-4) Likert scale (0 – not at all true/0 days, 1 – rarely true/1-2 days, 2 – sometimes true/3-4 days, 3 – usually true/5-6 days, and 4 – almost always true/every day). A total score ranges from 0 to 72 where 0 to 10 is considered to be a non-depressed range, 11 to 20 suggests minimal depression, 21 to 30 mild depression, 31 to 45 moderate depression, and 46 and above is likely to indicate severe depression (Zimmerman, Chelminsky et al., 2008).

The CUDOS is somewhat similar to the 9-item *Patient Health Questionnaire* (PHQ-9) which is a brief self-report measure assessing 9 DSM-IV symptoms of MDD using a Likert scale similar to the CUDOS. However, due to its brief form PHQ-9 has been criticised for not capturing potentially significant clinical information (Zimmerman & McGlinchey, 2008).

A validation study using an adult psychiatric outpatient population by Zimmerman and colleagues (Zimmerman, McGlinchey, & Chelminsky, 2008), reported that the CUDOS has high internal consistency/reliability (Cronbach's  $\alpha = .90$ ) and test-retest reliability ( $r = .92$ ), as well as good convergent and discriminant validity. As the CUDOS is a relatively new measure, there are no reported studies that have employed the CUDOS in the older adult population, to the researcher's current awareness.

#### 2.3.4 Informant version of the CUDOS (CUDOS-I).

The CUDOS-I (Appendix F) was constructed for the purpose of the present study by changing the pronoun in all of the items from 'I' to 'he/she'. No further changes to item content were made, and the format of responses and scoring principles remained the same as in the self-report CUDOS.

#### 2.3.5 The Health of the Nation Outcome Scales 65+.

The HoNOS 65+ (Burns et al., 1999; Appendix G) is a 12-item clinician-rated measure that assesses mental and social functioning outcomes in elderly people with mental health problems. The recommended rating period is for the preceding two weeks for both hospital outpatients and inpatients at admission. Each item is rated on a 5-point scale of severity (0-4) as follows: 0 – no problem, 1 – minor problem requiring no formal action, 2 – mild problem, 3 – problem of moderate severity, 4 – severe to very severe problem. Ratings 0 and 1 are considered not clinically significant whereas ratings 2, 3, and 4 are regarded as clinically significant. The individual scale items are: Behavioural disturbance, Non-accidental self injury, Problem drinking or drug use, Cognitive problems, Problems related to physical illness or disability, Problems associated with hallucinations and/or delusions or false beliefs, Problems associated with depressive symptoms, Other mental or behavioural problems, Problems with social or supportive relationships, Problems with activities of daily living, Overall problems with living conditions, and Problems with work and leisure activities.

The HoNOS 65+ has good inter-rater reliability and is a valid measure against other established scales which measure mental health problems in older people. A study by Burns et al. (1999) reported inter-rater reliability at .82 and moderate to high correlations of the individual HoNOS 65+ items with corresponding more detailed scales. Also, a New Zealand study by Gee, Croucher, and Beveridge (2010) reported an adequate concurrent validity and sensitivity to change. The HoNOS65+ is routinely collected in the Psychiatric Service for the Elderly, and indeed its use is mandated by the New Zealand Ministry of Health.

The present study employs four of the HoNOS 65+ items in order to operationalize some of the independent variables and to aid description of the sample. The results on item 5 (Physical illness or disability problems) are framed as physical frailty, those on item 7 (Problems with depressive symptoms) are operationalized as depression severity, and those on item 8 (Other mental and behavioural problems) as comorbidity. The results on item 6 (Problems associated with hallucinations and delusions) are used as a descriptor of the presence of clinically significant hallucinations and delusions in the current sample.

## 2.4 Procedure

The potential participant pool was a cohort of admissions to the Ward K2 over a one year period and the MHC over a seven-month period. Patients deemed appropriate for the study, were contacted in person by the researcher within the first two weeks of admission. After obtaining informed consent (consent form included in Appendix H), participants were asked to complete two self-report depression questionnaires, i.e., the CUDOS and the GDS-15. Both questionnaires were administered verbally by the researcher, in the patient's bedroom in Ward K2 or in an interview room at the MHC. The current study was part of a larger research project carried out by the Psychiatry of Old Age Academic Unit at the PMH. There was no compensation offered to participants.

For patients who consented, information was collected from an informant such as a family member or a friend who was appointed by the patient. The informant was contacted by phone by the researcher and offered a verbal explanation of the study purpose and procedure. After obtaining informed consent, the informant was asked to complete the GDSI-15 and the CUDOS-I, which were both sent out to them with a study information sheet (Appendix I) and a post-paid envelope. If the informant version questionnaires were not returned within two weeks, a remainder phone call was made.

Patients' demographic variables, including age and gender, as well as information concerning medical and psychiatric comorbidity, were extracted from the patients' medical records. Information about informants' gender and relationship to the patients was collected at the time of obtaining consent from the patients.

Ethical approval for this study was granted by the Upper South A Regional Ethics Committee (Ethics Reference Number: URB/09/03/009; see Appendix J).

## 2.5 Design and Statistical Analyses

Data were first entered into Microsoft Office Excel and then transferred into IBM SPSS Statistics (19.0) (2010). All data analyses were performed using SPSS. Data analyses comprised of descriptive statistics, t-tests, bivariate correlations, and multiple linear regression analyses.

Standard descriptive statistics were used to determine the demographic and clinical characteristics of the sample. Pearson product-moment correlations were calculated in order to assess the relationship between self-reported GDS-15 and self-reported CUDOS depression levels, as well as between informant-reported GDS-15 and informant-reported CUDOS depression scores. Two dependent t-tests were calculated to compare the self-report and informant ratings of depression severity on the GDS-15 and the CUDOS respectively. A

discrepancy score, namely the total score difference between the self-report and informant report GDS-15, was created by subtracting a total GDSI-15 score from a total self-report GDS-15 score; negative values indicate that the informant endorsed more depressive symptoms than the patient. A corresponding procedure was applied to create a total discrepancy score between the self-report and informant report CUDOS measures. The bivariate association of each independent variable with two dependent variables (a total score difference) was examined using independent t-tests and the Pearson product-moment correlation as appropriate. Guidelines for the interpretation of Pearson correlation coefficient were adopted as follows: values between 0 to .29 regarded as little if any correlation, between .3 to .49 as small or weak correlation, between .5 and .69 as moderate correlation, between .7 to .89 as strong correlation, and values between .9 and 1 as very strong correlation (Cohen, 1988).

Taking into account small sample size and a consequent need to reduce the number of predictors, only those independent variables which were found to be significantly associated with dependent variables were entered into multivariate linear regression. The  $p$  value for including the independent variables in to the regressions was  $p < .05$ . Subsequently, two separate simultaneous multiple regressions were conducted. The first one used the total GDS-15 discrepancy score as a criterion and independent variables that were significantly associated with the total GDS-15 discrepancy score as predictors. Correspondingly, a second regression used the total CUDOS discrepancy score as criterion and independent variables that were found to be significantly associated with the total CUDOS discrepancy score as predictors.

Cohen's kappa coefficients were calculated to assess the proportion of agreement, beyond the amount which is expected by chance alone, between patients and informant responses on each item of the GDS-15 and the CUDOS. The range for kappa is from less than 0 to 1, with



a value of 1 indicating perfect agreement. Guidelines for interpreting the kappa coefficient suggest that kappa values greater than 0.8 indicate almost perfect agreement, values between 0.6 and 0.8 indicate substantial agreement, values between 0.4 and 0.6 indicate moderate agreement, values between 0.21 and 0.4 indicate fair agreement, values between 0.2 and 0.0 indicate slight agreement, and values less than 0.0 indicate poor agreement (Landis & Koch, 1977). The standard error used for kappa is that given by Fleiss, Cohen, & Everitt (1969). Fleiss and colleagues (1969) recommended that when the categories are nominal, Cohen's simple unweighted coefficient is the only form of kappa that can be used meaningfully, whereas when the categories are ordinal the weighted kappa coefficients should be computed. Considering that the GDS-15 is a nominal scale and the CUDOS is an ordinal scale, the unweighted kappa coefficients were calculated for all of the GDS-15 items and the weighted kappa coefficients were calculated for the CUDOS items.



## CHAPTER THREE

### 3. Results

#### 3.1 Descriptive Characteristics of the Sample

##### 3.1.1 Response rate.

The sample analysed in the present study consisted of patients for whom an informant rating was successfully collected. Where the same individual had data collected on both the inpatient ward and the day-hospital, only data from the inpatient ward was used in the analysis.

For the inpatient ward (K2) 117 patients were noted as admitted, of whom 44 (45%) completed the questionnaire. Of those who did not participate approximately a quarter were not available or excluded by staff (e.g. discharged, deceased, did not speak English, cognitively impaired or too unwell), while approximately three quarters declined. Informant questionnaires were successfully gathered for 15 (34%) of the participants (e.g. they were willing and able to nominate an informant, who was in turn contactable and willing to complete the questionnaire).

For the day-hospital (MHC) 90 patients were admitted, of whom 90% (81) completed the questionnaire. Six were excluded from this analysis because they had been participated on K2. Collateral source information was successfully gathered for 21 (28%) of the remaining participants.

##### 3.1.2 Description of sample.

Table 1 summarises the demographic information and the presence of clinically significant psychiatric symptoms for the inpatient Ward K2 ( $N=15$ ) and the day-hospital MHC ( $N=21$ ) samples separately as well as for the entire sample. Visual inspection of descriptive

characteristics data suggests that their distributions were similar for the Ward K2 and the MHC samples. Between-groups comparison of demographic and clinical descriptive variables revealed no significant difference in age, gender, ethnicity, and level of depression. However, there was a significant difference in anxiety level [ $t(34) = -2.59, p < .05$ ] and presence of clinically significant hallucinations and delusions [ $t(34) = 2.53, p < .05$ ]. Anxiety levels displayed by patients from the MHC were clinically significantly higher ( $M = 1.95, SD = 1.16$ ) than those of Ward K2 patients ( $M = 1.27, SD = 1.44$ ). At the same time, patients in Ward K2 displayed clinically significant hallucinations and delusions ( $M = 1.2, SD = 1.42$ ) to a greater degree than those in the MHC ( $M = .1, SD = .44$ ). Despite these differences between the two locations, considering the small overall sample size, the main data analyses were subsequently conducted using the total sample.

The average age of all of the patients was 76 years of age and all of them endorsed NZ European ethnicity. A majority of patients were females (64%) and most of them had clinically significant symptoms of depression (72%) and anxiety (61%) as assessed by the HoNOS 65+. Only some of the patients (22%) were recognised to have clinically significant hallucinations and delusions on the HoNOS 65+. As none of the patients had a diagnosis of cognitive impairment it was assumed that all of the patients had normal cognitive functioning.

### 3.2 Description of Variables

The following variables were investigated as potential predictors of any differences between self and informant reports of depressive symptoms: Age, Gender, Location (inpatient or day-hospital), Symptoms of Depression, Physical Frailty, Psychiatric Comorbidity, Informant's relationship, and Informant's Gender.

Table 1  
*Descriptive Characteristics of the Ward K2 Sample, the Mabel Howard Clinic (MHC) Sample and the Total Sample*

Characteristics	K2 Sample ( <i>N</i> =15) Mean ( <i>SD</i> ) or <i>n</i> (%)	MHC Sample ( <i>N</i> =21) Mean ( <i>SD</i> ) or <i>n</i> (%)	Total Sample ( <i>N</i> =36) Mean ( <i>SD</i> ) or <i>n</i> (%)
Gender			
Female %	10 (67)	13 (62)	23 (64)
Male %	5 (33)	8 (38)	13 (36)
Ethnicity			
NZ European	15 (100)	21 (100)	36 (100)
NZ Maori	0 (0)	0 (0)	0 (0)
Age (years)	75.3 (6.4)	76.1 (6.8)	75.8 (6.5)
HoNOS 65+ Symptoms			
Depression %	10 (67)	16 (76)	26 (72)
Anxiety %	6 (40)	16 (76)	22 (61)
Hallucination and Delusions %	7 (47)	1 (5)	8 (22)

Age of patients was computed by subtracting their date of birth from the admission date to either Ward K2 or the MHC. Age (i.e., current age), was used in all of the analyses as a continuous variable. Gender and Location were dichotomised (Gender: 0 – female, 1 – male; Location: 0 – Ward K2, 1 - MHC). Comorbidity was operationalized as the level of clinically significant anxiety symptoms as measured by the clinician-rated HoNOS 65+. Symptoms of Depression were also measured with HoNOS 65+ and operationalized as the level of clinically significant symptoms of depression. Both Symptoms of Depression and

Comorbidity were treated as continuous variables. Descriptive characteristics of Age, Gender, Location, Symptoms of Depression, and Comorbidity are presented in Table 1.

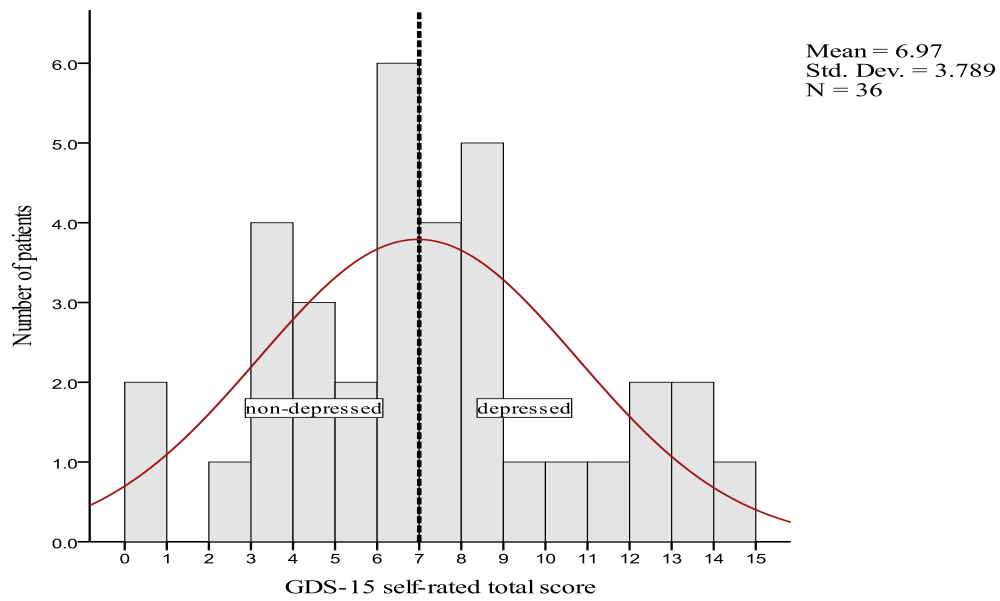
The Physical Frailty score was defined as the level of physical illness or disability as assessed by HoNOS 65+ and it was employed in all of the analyses as a continuous variable. Sixty seven percent of all of the patients had clinically significant physical health problems associated with restriction of their activity or mobility. The distribution of Physical Frailty was similar for Ward K2 and the MHC. Additionally, between-groups comparison revealed no significant difference in levels of Physical Frailty.

The patients' relationship to their appointed informants was labelled as the Source Type and dichotomised as partner or non-partner. A small sample size did not allow for a further differentiation of the Source Type. Thirty six percent ( $n = 13$ ) of informants were patients' partners. The non-partner category comprised of daughters ( $n = 11$ ), sons ( $n = 4$ ), siblings ( $n = 3$ ), friends ( $n = 3$ ), a nephew ( $n = 1$ ), and an ex-partner ( $n = 1$ ). The Source Gender was the gender of the appointed informant. Sixty seven percent of informants were females.

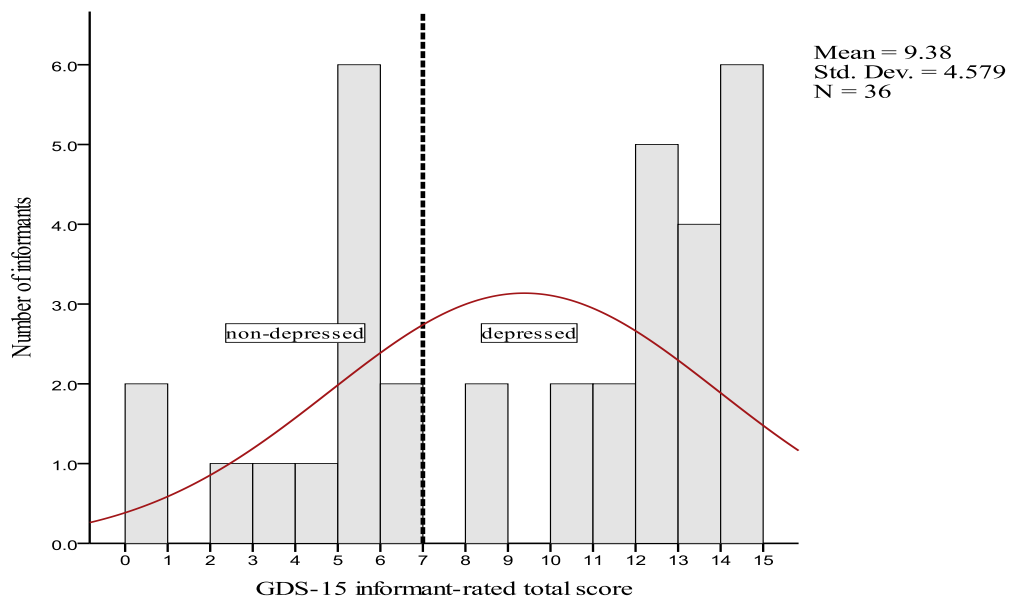
### 3.3. Descriptive Data for Measures of Depression

#### 3.3.1 Distribution of scores.

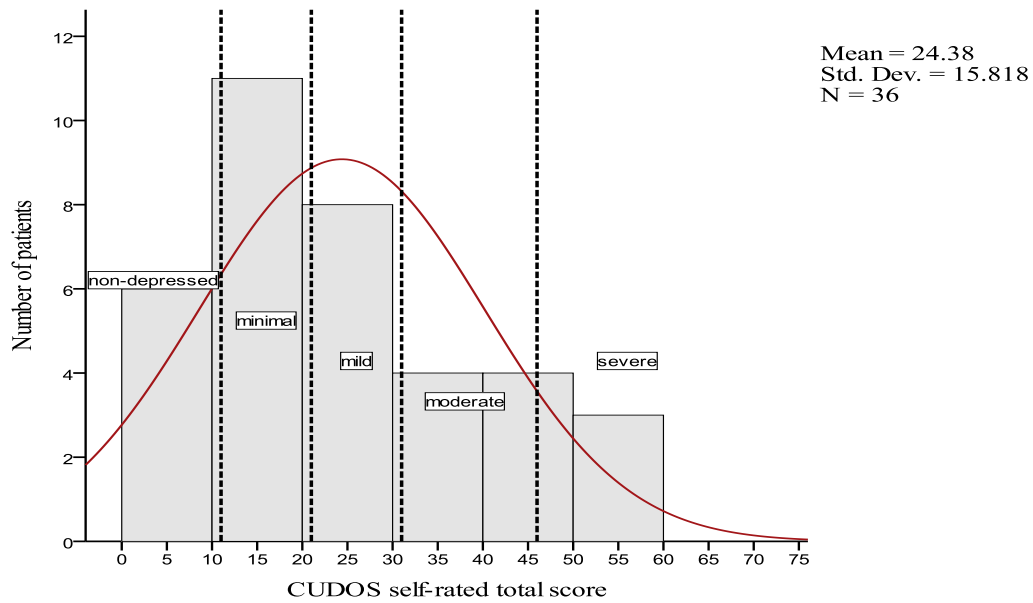
Figures 1 – 4 illustrate the distribution of scores on both self and informant versions of both GDS-15 and CUDOS. As shown in Figure 1 and 4, the scores for the self-reported GDS-15 and the informant reported CUDOS appear to be relatively normally distributed, while the scores for the informant-rated GDS-15 are negatively skewed (Figure 2). Positive skew is evident for the self-reported CUDOS (Figure 3).



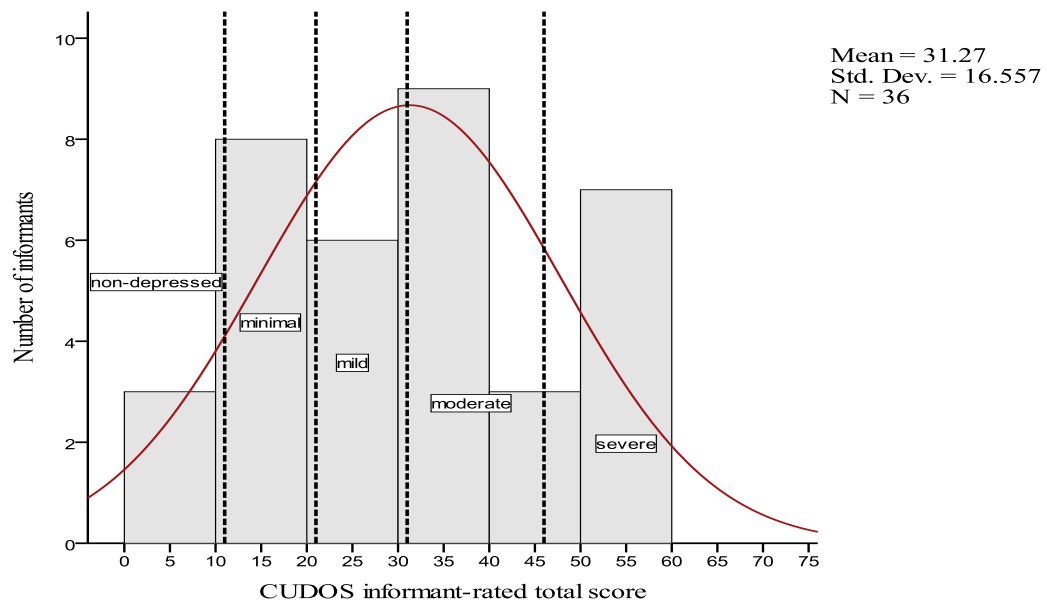
*Figure 1.* Distribution of scores on self-rated GDS-15. Dotted line marks a cut-off point of 7 that differentiates between non-depressed and depressed ranges.



*Figure 2.* Distribution of scores on informant-rated GDS-15. Dotted line marks a cut-off point of 7 that differentiates between non-depressed and depressed ranges.



*Figure 3.* Distribution of scores on self-rated CUDOS. Dotted lines indicate cut-off points between non-depressed, minimal, mild, moderate, and severe depressive symptomatology (11, 21, 31, and 46 respectively).



*Figure 4.* Distribution of scores on informant-rated CUDOS. Dotted lines indicate cut-off points between non-depressed, minimal, mild, moderate, and severe depressive symptomatology (11, 21, 31, and 46 respectively).



### 3.3.2 Measures of central tendency.

Scores on the GDS-15 were summed to provide a total score for self-reported depressive symptoms with an observed range of 0 through to 15; the mean was 6.97 ( $SD = 3.79$ ), and the median was 6.78. Both the mean and the median are approaching the cut-off score of 7 that differentiate between non-depressed and depressed individuals. Also, scores on the 18 items of the self CUDOS were summed to provide a total score with an observed range of 2 through to 59, the mean was 24.38 ( $SD = 15.82$ ), and the median was 20.5. The mean is within mild depression severity range and the median within minimal depression severity range.

Correspondingly, scores on the GDSI-15 were summed to provide a total score for informant-reported symptoms of depression with an observed range of 0 through to 15, a mean of 9.38 ( $SD = 4.58$ ), and median of 11.39. Scores on an informant version of CUDOS were also summed to provide a mean total score of 31.27 ( $SD = 16.56$ ), with an observed range of 4 through to 59, and median of 30.5.

### 3.3.3 Correlations.

Correlations were conducted to assess how scores on the measures related to each other. The first pair of correlations assessed the association across the two instruments for ratings made by the same rater. Pearson product-moment correlations between the total self-report GDS-15 and the total self-report CUDOS were calculated. There was a significant (criterion  $p < .05$ ), moderate positive relationship between these self-report measures,  $r(34) = .64$ , ( $p < .001$ ), which suggests that patients reports of depressive symptoms are fairly consistent on both questionnaires. Whereas Pearson product-moment correlation between the total informant-report GDS-15 and informant-report CUDOS was  $r(34) = .82$ , ( $p < .001$ ), revealing a strong positive, significant relationship between scores on these questionnaires.

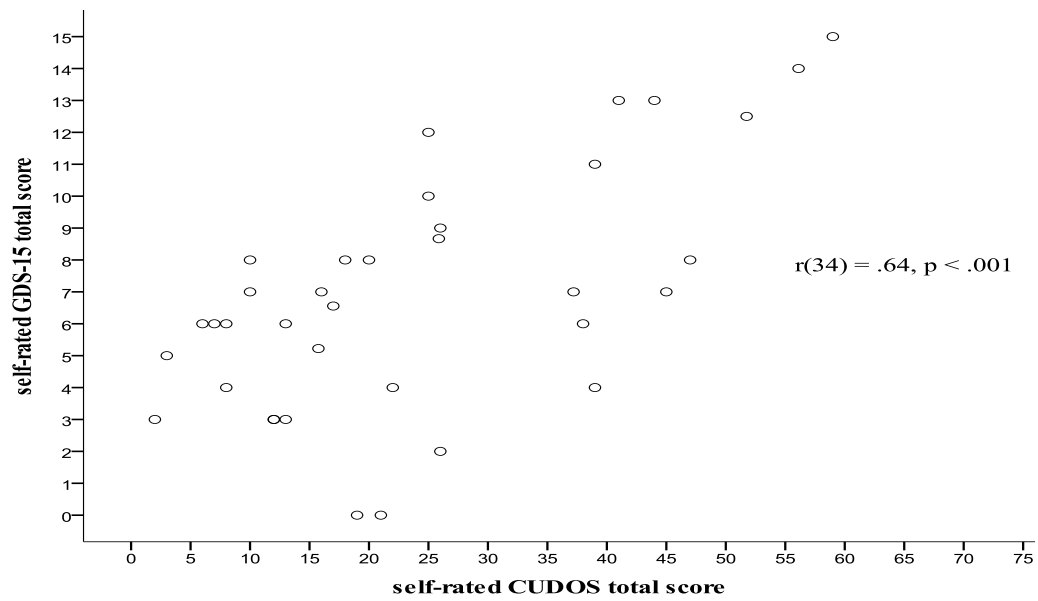


Figure 5. Scatter plot representing correlation between self-reported GDS-15 and self-reported CUDOS.

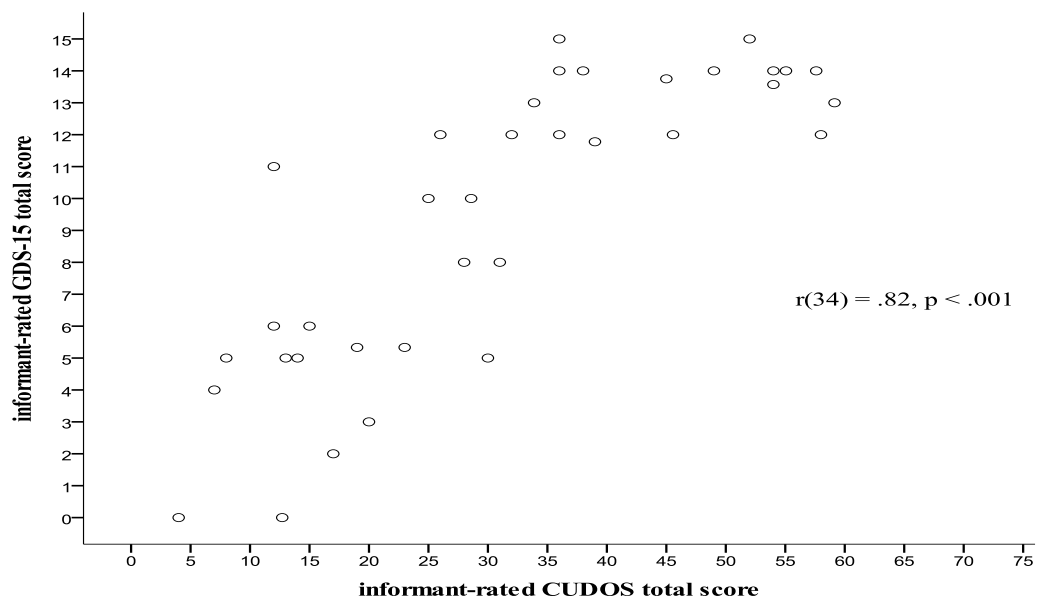


Figure 6. Scatter plot representing correlation between informant-reported GDS-15 and informant-reported CUDOS.

This indicates that informants' reports of depressive symptoms are consistent across both measures. Figures 5 and 6 present scatter plots representing correlation between self-reported GDS-15 and self-reported CUDOS, and between informant-reported GDS-15 and informant-reported CUDOS respectively. Both of these plots show positive correlation between questionnaires and display lack of other systematic variation between them.

The second set of correlations assessed the association between the level of depressive symptoms rated by the individual and that rated by their informant. Pearson product-moment correlation was also performed between a self GDS-15 total and an informant GDSI-15 total, using an alpha level of .05. A moderate, positive relationship between a self GDS-15 total and an informant GDSI-15 total was significant,  $r(34) = .65$  ( $p < .001$ ), suggesting that patients' and informants' ratings of depressive symptoms using GDS-15 were similar. Similarly, Pearson product-moment correlation was performed between a total self-report CUDOS and a total informant CUDOS, using an alpha level of .05. A small positive relationship between a total self-report CUDOS and informant-report CUDOS was significant,  $r(34) = .39$ , ( $p = .017$ ). This indicates that informants' reports of patients' levels of depressive symptoms are relatively poorly correlated with self-reported levels of depression when using the CUDOS.

Figures 7 and 8 present scatter plots representing correlation between self-reported GDS-15 and informant-reported GDS-15, and between self-reported CUDOS and informant-reported CUDOS respectively.

In summary, there was a moderate to strong relationship between the two instruments when rated by the same person. For the GDS-15 there was a moderate relationship between patient and informant ratings whereas for the CUDOS there was a significant but smaller relationship between patient and informant ratings.

### 3.4 Differences between Self and Informant Reports of Depressive Symptoms

To test the first hypothesis that informants would report significantly more depressive symptoms than patients, dependent *t*-tests were calculated to compare the self-report and informant ratings of depression. This was conducted for each of the two depression measures (the GDS-15 and the CUDOS) separately. The comparison across the two analyses allowed assessment of the second hypothesis that the overall discrepancy between patient's and informant's ratings would be lower on a measure asking about presence/absence of depressive symptoms (GDS-15) than on a measure asking about frequency of these symptoms (CUDOS). Assumptions of normality were met.

For the GDS-15, the mean total score for the self-report GDS-15 ( $M = 6.97$ ,  $SD = 3.97$ ) was lower than the mean total score for the informant version of the GDS-15 ( $M = 9.38$ ,  $SD = 4.59$ ). The mean total discrepancy score of -2.41 between the self and informant reports of depression was found to be statistically significant from zero [ $t(35) = -4.05$ ,  $p < .001$ ] with a 95% confidence interval of (-3.62)–(-1.20). The obtained effect size for information source was  $d = .67$  (medium; Cohen, 1988) for the GDS-15.

Regarding CUDOS, mean for the total self-report CUDOS ( $M = 24.38$ ,  $SD = 15.82$ ) was lower than the mean for the total score for the informant version of CUDOS ( $M = 31.27$ ,  $SD = 16.56$ ). The mean total discrepancy score of -6.89 between the self and informant reports of depression was also found to be statistically significant [ $t(35) = -2.38$ ,  $p = .023$ ] with a 95% confidence interval of (-12.76)–(-1.01). The obtained information source effect size ( $d = .40$ ) was in between the conventional boundaries of a small and a medium effect size.

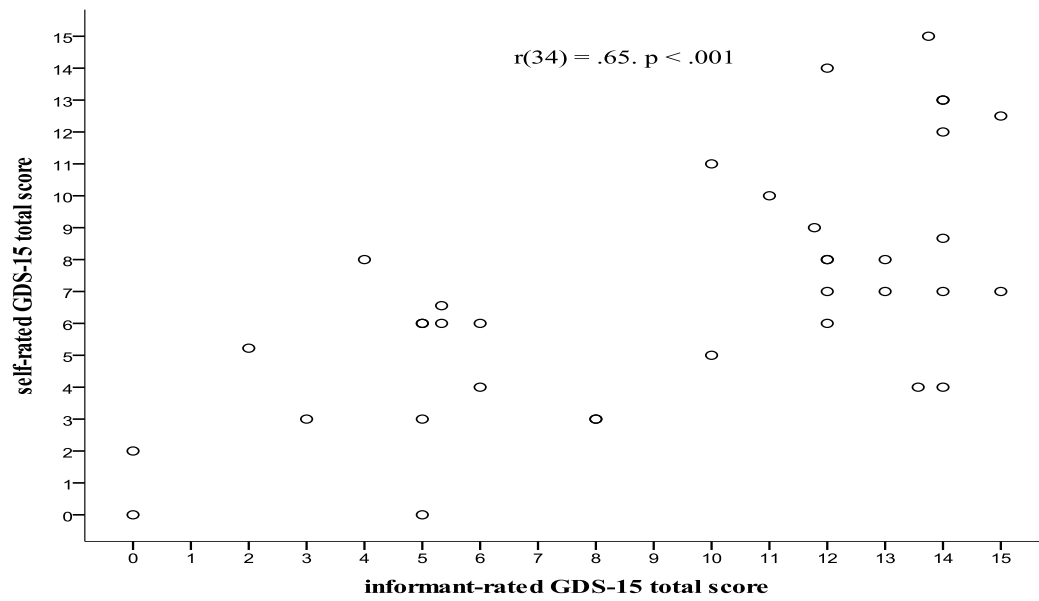


Figure 7. Scatter plot representing correlation between self-reported GDS-15 and informant-reported GDS-15.

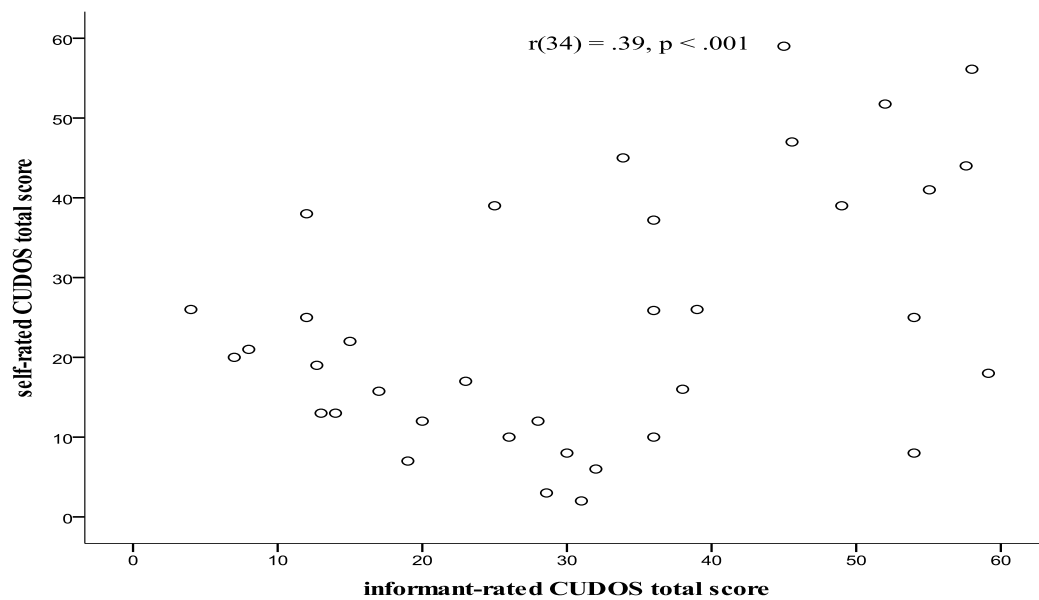


Figure 8. Scatter plot representing correlation between self-reported CUDOS and informant-reported CUDOS.

Overall, both t-tests indicated that informants rated greater amount of depressive symptoms than did the individual themselves. Comparing effect sizes, that discrepancy was greater for the GDS-15 than for the CUDOS.

### 3.5 Associations between Independent Variables and Total Discrepancy Scores between Self and Informant Reports of Symptoms of Depression

It was hypothesised that discrepancy between patient's and informant's reports of depressive symptoms would be positively correlated with patient's physical frailty, psychiatric comorbidity, and older age. Also, discrepancy between patient and informant reports of depressive symptoms was expected be higher for male and non-partner informants. As a first step correlations or *t*-tests between the discrepancy score and each of these variables were conducted. Table 2 presents the associations between the independent variables and the GDS-15 and the CUDOS total discrepancy scores, as well as their significance value.

For the GDS-15, patients' Gender and Psychiatric Comorbidity were found to be significantly associated with the GDS-15 total discrepancy score. The difference between self and informant GDS-15 was more likely to be higher for male patients than for female patients and was more likely to increase with an increase in patients' levels of psychiatric comorbidity.

For the CUDOS, patient's Gender and Location (inpatient, day-hospital) were found to be significantly associated with the CUDOS total discrepancy score. This indicates that for male patients the difference between self and informant CUDOS is likely to be higher than for female patients and also this difference is likely to be higher for patients from the day-hospital (MHC) than for patients from the inpatient Ward K2.

Table 2

*Association between Independent Variables and total discrepancy scores between self and informant GDS-15 and CUDOS*

Independent Variable	Association with GDS-15 total discrepancy scores		Association with CUDOS total discrepancy scores	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
Age	.088	<i>ns</i>	.032	<i>ns</i>
Symptoms of Depression	-.022	<i>ns</i>	.185	<i>ns</i>
Physical Frailty	-.093	<i>ns</i>	-.011	<i>ns</i>
Comorbidity	.380	.022*	.124	<i>ns</i>
	<i>t</i>	<i>p</i>	<i>t</i>	<i>p</i>
Gender	2.114	.042*	2.079	.045*
Location	-.100	<i>ns</i>	2.617	.013*
Source Type	.264	<i>ns</i>	1.383	<i>ns</i>
Source Gender	.126	<i>ns</i>	.466	<i>ns</i>

*Note.* \*  $p < .05$ , *ns* – non-significant

### 3.6 Prediction of Total Discrepancy Scores between Self and Informant

#### Reports of Symptoms of Depression

As a second step to examine the factors associated with discrepancy scores, two separate, simultaneous multiple regressions were conducted using the GDS and the CUDOS discrepancy scores as criteria. Gender and Comorbidity were used to predict the GDS-15 total discrepancy score and Gender and Location were used to predict the CUDOS total discrepancy score (because only these variables were found to be significantly associated with the respective discrepancy scores in univariate analyses; see above).

### 3.6.1 Prediction of the GDS-15 total discrepancy scores.

A simultaneous multiple regression was conducted using the GDS-15 total discrepancy scores as a criterion and patients' Gender and Psychiatric Comorbidity as predictive variables. Analysis of assumptions revealed no outliers with a standard residual  $> 3$ , and no outliers with an extreme Mahalanobis distance score  $> 13.816$  ( $p < .001$ ). Table 3 displays the unstandardised regression coefficients ( $B$ ), the standard error of the unstandardised regression coefficients ( $SE$ ), standardised regression coefficients ( $\beta$ ), and their significance levels ( $p$ ). The analysis resulted in  $R = .449$ ,  $R^2 = .204$ , adjusted  $R^2 = .153$ ,  $F(2, 33) = 4.160$ , ( $p = .024$ ).

Neither patients' Gender nor Psychiatric Comorbidity scores were significant, unique predictors of the GDS-15 total discrepancy scores.

Table 3  
*Simultaneous Multiple Regression of Gender and Comorbidity as Predictors of the GDS-15 Total Discrepancy Score*

Variable	$B$	$SE$	$\beta$	$p$
Gender	-1.831	1.196	-.250	.135
Comorbidity	.835	.445	.306	.069
Constant	-3.142	1.109		.008

*Note.* Adjusted  $R^2 = .153$

### 3.6.2 Prediction of the CUDOS total discrepancy scores.

A second simultaneous multiple regression was conducted with the CUDOS total discrepancy scores as a criterion and patients' Gender and Location (inpatient, day-hospital) as predictive variables. Analysis of assumptions revealed no outliers with standard residual  $> 3$ , and no outliers with an extreme Mahalanobis distance score  $> 13.816$  ( $p < .001$ ).



Table 4 displays the unstandardised regression coefficients ( $B$ ), the standard error of the unstandardised regression coefficients ( $SE$ ), standardised regression coefficients ( $\beta$ ), and their significance levels ( $p$ ). The analysis rendered  $R = .517$ ,  $R^2 = .268$ , adjusted  $R^2 = .223$ ,  $F(2, 33) = 6.031$ , ( $p = .006$ ).

Both Gender and Location were significant, unique predictors of CUDOS total discrepancy scores. As noted above discrepancy between self and informant CUDOS was greater for male than for female patients and the discrepancy was higher for patients from the MHC day-hospital than for patients from the inpatient K2 Ward.

Table 4  
*Simultaneous Multiple Regression of Gender and Location as Predictors of the CUDOS Total Discrepancy Score*

Variable	$B$	$SE$	$\beta$	$p$
Gender	-11.284	5.316	-.317	.041*
Location	-13.682	5.179	-.394	.013*
Constant	5.171	4.330		.241

*Note.* Adjusted  $R^2 = .223$ , \*  $p < .05$

### 3.7 Item-level Interrater Reliability for the Self and Informant GDS-15 and the Self and Informant CUDOS

The fifth hypothesis was that rates of agreement would be higher on items that refer to symptoms more easily observable with clear behavioural manifestation (e.g., changes in appetite, sleep patterns and energy levels) than on items that referred to intrapsychic symptoms (e.g. feelings of guilt and worthlessness). To assess this, an interrater reliability analysis using kappa statistics was performed to determine the rates of agreement among

raters on each GDS-15 and CUDOS items. The unweighted kappa coefficients, between the self and informant rating, for each of the GDS-15 items were calculated and for each of the CUDOS items the weighted kappa coefficients between patients' and informants' rating were computed. Based on the previous research, each of the GDS-15 and CUDOS items were arbitrary categorized as items relating to observable or intrapsychic symptoms of depression. Some of the GDS-15 items were categorized as both because the way they were phrased related to both types of symptoms.

### 3.7.1 Interrater reliability for the GDS-15.

The unweighted kappa coefficients for each of the GDS-15 items, as well as their standard errors of measurement and confidence intervals are presented in Table 5. Of the 15 items for which patients' and informants' reports were compared, moderate agreement ( $0.6 > \kappa \geq 0.41$ ) was observed for three items, fair agreement ( $0.41 > \kappa \geq 0.21$ ) was seen for seven items, and slight agreement ( $0.21 > \kappa \geq 0$ ) was found for five items.

### 3.7.2 Interrater reliability for the CUDOS.

The kappa coefficients with linear weighting, between the self and informant rating, for each of the CUDOS items, their standard error of measurement, and confidence intervals are presented in Table 6. Of the 18 CUDOS items, agreement was moderate ( $0.6 > \kappa \geq 0.41$ ) for two items, fair ( $0.41 > \kappa \geq 0.21$ ) for six items, and slight ( $0.21 > \kappa \geq 0$ ) for the remaining ten items.

Table 5  
*Unweighted Kappa for the GDS-15*

GDS Item	Observed Kappa	Standard Error	.95 Confidence Interval	
			Lower Limit	Upper Limit
1. life satisfaction †♦	.489***	.141	.212	.765
2. lack of interest ♦	.127*	.172	< 0	.464
3. lack of pleasure †	.395**	.159	.083	.707
4. boredom ♦	.384**	.141	.108	.660
5. mood †♦	.157*	.131	< 0	.414
6. fear about future †	.056*	.153	< 0	.356
7. mood/happiness †♦	.264**	.140	< 0	.538
8. helplessness †	.243**	.175	< 0	.586
9. lack of interest ♦	.406**	.156	.100	.712
10. memory problems ♦	.100*	.161	< 0	.415
11. life satisfaction †♦	.427***	.135	.162	.692
12. worthlessness †	.591***	.136	.324	.857
13. lack of energy ♦	.364**	.180	.011	.717
14. hopelessness †	.118*	.130	< 0	.373
15. worthlessness †	.343**	.157	.035	.651

*Note.* \*slight agreement, \*\*fair agreement, \*\*\*moderate agreement, ♦ observable symptoms, † intrapsychic symptoms

Table 6  
*Kappa with Linear Weighting for the CUDOS*

CUDOS Items	Observed Kappa	Standard Error	.95 Confidence Interval	
			Lower Limit	Upper Limit
1. depressed mood †	.182*	.093	< 0	.364
2. lack of interest ♦	.128*	.119	< 0	.362
3. decreased appetite ♦	.313**	.109	.099	.527
4. increased appetite ♦	.027*	.085	< 0	.193
5. decreased sleep ♦	.336**	.118	.105	.566
6. increased sleep ♦	.140*	.157	< 0	.449
7. motor agitation ♦	.167*	.114	< 0	.389
8. motor retardation ♦	.190*	.113	< 0	.412
9. low energy ♦	.251**	.104	.046	.455
10. feelings of guilt †	.111*	.125	< 0	.357
11. feelings of failure †	.061*	.129	< 0	.315
12. difficulties concentrating ♦	.233**	.098	.041	.425
13. indecisiveness ♦	.134*	.113	< 0	.355
14. thoughts about death †	.453***	.112	.233	.674
15. suicidal thinking †	.441***	.134	.177	.704
16. hopelessness †	.209**	.111	< 0	.427
17. impairment of functioning ♦	.291**	.097	.101	.481
18. quality of life †	.129*	.128	< 0	.379

*Note.* \*slight agreement, \*\*fair agreement, \*\*\*moderate agreement, ♦ observable symptoms, † intrapsychic symptoms



## CHAPTER FOUR

### 4. Discussion

The present study examined discrepancy between reports of depressive symptoms of elderly individuals and their family or friends as informants. It also looked at factors potentially affecting this discrepancy related to characteristics of the older individual, informant, type of measure assessing depression, and type of depressive symptoms. Description of findings, the present study's strengths and limitations, implications for clinical practice and research, and possible future direction for further research are described below.

#### 4.1 Summary of Findings

1 *Did informants report significantly more depressive symptoms than patients?*

The present study found that there was a significant discrepancy between patient and family informant reports of depressive symptomatology. Informants reported significantly more depressive symptoms than the psychogeriatric patients themselves on two depression measures, namely the GDS-15 and the CUDOS.

2 *Was the overall discrepancy between patient's and informant's ratings lower on a measure relating to presence/absence of depressive symptoms (GDS-15) than on a measure relating to frequency of these symptoms (CUDOS)?*

In contrast to expectations, the discrepancy was greater on the GDS-15 than on the CUDOS.

- 3 *Was the discrepancy between patient's and informant's reports of depressive symptoms positively correlated with patient's physical frailty, psychiatric comorbidity, and older age?*

Patient's physical frailty and age was not associated with the magnitude of discrepancy between patient and informant reports of depressive symptomatology on either GDS-15 or CUDOS.

Patient's psychiatric comorbidity was positively associated in a univariate analysis with discrepancy of reports for the GDS-15. However, psychiatric comorbidity was not a significant unique predictor of GDS-15 discrepancy after regression analysis was conducted. Patient's psychiatric comorbidity did not predict discrepancy in reports on CUDOS.

- 4 *Was discrepancy between patient and informant reports of depressive symptoms higher for males and for non-partner informants?*

Informant's gender and type of relationship to the patient did not predict the magnitude of discrepancy between patient and informant reports of depressive symptomatology on either the GDS-15 or the CUDOS.

There was a significantly greater discrepancy score for male participants for both the CUDOS and GDS-15 in univariate analyses. Participant gender remained a significant unique predictor for the CUDOS score in a regression analysis, but not for the GDS-15.

- 5 *Were the rates of agreement higher on items that referred to symptoms more easily observable with clear behavioural manifestation (e.g., changes in appetite, sleep patterns*

*and energy levels) than on items that referred to intrapsychic symptoms (e.g. feelings of guilt and worthlessness)?*

Surprisingly, rates of agreement were somewhat higher on items that assessed suicidal ideation and intent as well as feelings of worthlessness and life satisfaction as opposed to items that assessed symptoms with clear behavioural manifestation.

The present study took place at two locations, a day-hospital and an inpatient ward. The discrepancy scores were greater for the day-hospital participants than for the inpatient participants, however this was observed for the CUDOS only.

## 4.2 Interpretation and comparison with previous research

### 4.2.1 Overall discrepancy between patient and informant reports.

The present study demonstrated significant discrepancies between self- and informant reports of depressive symptoms on both depression questionnaires that were used to assess these symptoms. These findings are consistent with several previous studies (e.g. Burke et al., 1998; Davison et al., 2009; Snow, Cook, Lin, Morgan, & Magaziner, 2005).

Importantly, it was confirmed that informants consistently reported significantly more depressive symptoms than did patients themselves on both the GDS-15 and the CUDOS. In a different sample; AD and cognitively intact community-dwelling older individuals, Burke et al. (1998) also found that informants consistently perceived more depressive symptoms than subjects on self-report questionnaires. Similarly, McAvay et al. (2004) in a sample of non-demented medical patients and Teri and Wagner (1991) in a sample of AD patients reported that overall, informants tended to report more depressive symptoms than patients. However both of these studies used clinician-rated methods of assessing depressive symptoms.



Not all of the studies are consistent with present findings. Bassett and colleagues (1990) did not find any overall significant differences between community-dwelling older women and their informants ratings of depression on CES-D. It is possible that the overall difference was non-significant in their study due to low variability in depression scores, as the majority of their sample scored within the non-depressed range (444 women out of 538) and the overall mean score for self-report CES-D was considerably low ( $M = 7.49$ ; CES-D possible score range 0 to 60). Overall, the current study is consistent with previous studies and provides further evidence that family members of non-demented patients display an overall tendency to report more depressive symptoms than patients on self-reported depression scales. Considering that the present study was carried out in a secondary care psychogeriatric setting, it further demonstrates that this tendency is not only present among community-dwelling or medically ill individuals but also among individuals with mental health difficulties.

#### 4.2.2 Discrepancy across measures

It was hypothesised that because of its dichotomous response format that asks about presence/absence of symptoms, GDS-15 would be easier to rate and consequently the discrepancy in reports would be lower than on CUDOS which asks about frequency of symptoms. Contrary to initial predictions, the discrepancy between reports of depressive symptoms was found to be greater on the GDS-15 than on the CUDOS. This was indicated by a medium effect size for total discrepancy scores on GDS-15 as compared to small approaching medium effect size for total discrepancy scores on CUDOS.

It is possible that greater discrepancy is due to specific differences between GDS-15 and CUDOS. The GDS-15 does not include any items that assess somatic or suicidal symptoms of depression as these were excluded by scale authors to increase accuracy of geriatric

depression assessment, nor does it specifically ask about depressed mood. In addition, closer analysis of the content of some of the GDS-15 items makes it questionable whether these assess a singular construct of depression. Items such as “Are you afraid that something bad is going to happen to you?” or “Do you prefer to stay at home, rather than going out and doing new things” could easily be used as an assessment of anxiety. Moreover, several items such as “Are you basically satisfied with your life” or “Do you think it is wonderful to be alive now?” are ambiguous and it is open to discussion whether these assess dissatisfaction with life related to depression, anxiety, or any other mental health problem. The CUDOS, on the other hand, asks explicitly for all of the DSM-IV-TR symptoms of depression e.g. “I felt sad or depressed” or “I wish I was dead”. Furthermore, the item assessing impairment clearly states that it is related to depressive symptoms; “Overall, how much have symptoms of depression interfered with or caused difficulties in your life during the past week?”. Thus, it is possible that ambiguity of the GDS-15 items increased the magnitude of raters’ discrepancy.

In addition, GDS-15 items are phrased in present tense, which can potentially increase discrepancy in two ways. Firstly, some of the questions when asked in present tense appear to be relating to more global constructs e.g. “Are you in good spirits most of the time” or “Do you think that most people are better off than you are?”. This could potentially further increase ambiguity around what is being assessed through these questions and consequently increase the discrepancy. Secondly, the one-week time frame regarding the presence of depressive symptoms is specified only in the first sentence and questions that follow are in present tense, which creates a confusion around the specific period of time that GDS-15 items relate to. Thus, it is possible that not all of the patients and informants had a one week

timeframe in mind when answering all of the GDS-15 questions. This could have additionally increased the discrepancy in reports observed on the GDS-15.

Although the possible range of scores is greater on CUDOS than it is on GDS-15, it is worth noting that variability of scores on CUDOS appears to be much greater than on GDS-15 for both self- and informant reports. Thus, it is possible that a higher standard deviation of scores on CUDOS decreased an overall effect size for discrepancies of self- and informant reports observed on CUDOS and subsequently the effect size observed for GDS-15 appeared to be relatively higher.

#### 4.2.2 Discrepancy and patient characteristics.

Patient's male gender was significantly associated with discrepancy in reports of depressive symptoms on both GDS-15 and CUDOS. However, it significantly predicted this discrepancy only when CUDOS was used. It has been noted that affective symptoms are often underreported by older individuals due to a variety of reasons such as concern among older people about the stigma of mental illness, lack of insight into their mood, a tendency to normalize their depressed mood, or a reluctance to disclose affective symptoms (e.g. Brodaty et al., 2005; Davison et al., 2009; Lyness et al., 1995). Although not conclusive, there is also some evidence suggesting that males in general have a tendency to underreport depressive symptoms (e.g. Blair-West, Cantor, Mellsop, & Eyeson-Annan, 1999; Steffens et al., 2000). Thus, this raises a possibility that in the present study older males had a tendency to underreport depressive symptoms, which consequently affected the discrepancy self- and informant reports of depressive symptoms.

Greater psychiatric comorbidity was positively associated with discrepancy of reports of depressive symptoms on the GDS-15. However when patient's gender was accounted for, comorbidity did not significantly predict this discrepancy in reports. More participants would

be needed to tease out the inter-relationship between psychiatric co-morbidity and gender to help interpret this pattern of results. However combining a possibility that males have a tendency to underreport depressive symptoms with ambiguity of the GDS-15 items, it raises a possibility that with greater comorbidity informants would endorse more symptoms on the GDS-15 than patients. This in consequence would increase a discrepancy between GDS-15 scores of male patients with greater comorbidity and their informants.

Patient's physical frailty, age, and severity of depression did not predict discrepancy between patient and informant reports of depressive symptoms on either of the depression questionnaires. A study that implicated patient's medical morbidity and functional disability in differences between reports of depressive symptoms (McAvay et al., 2004) used more comprehensive measures to assess these constructs than these used in the present study. It is possible that physical frailty operationalized as a score on a single HoNOS 65+ item was too simplistic and not sufficient to detect its influence on discrepancy between patient and informant reports of depressive symptoms.

A study by Cacchione et al. (2003), and another by Ross et al. (1997), found that an increase in patient's age predicted greater difference between patient and informant reports of depression. However, the patient sample in both of these studies was comprised of individuals with dementia. Thus, it is possible that an increase in patient age was to some extent confounded with an increase in dementia severity. This could mean that greater difference in reports was potentially reflected by the patient's increase in inaccuracy of reports and not necessarily by their greater age. If that was the case, a lack of significant association between patient's age and the magnitude of discrepancy in self- and informant reports of depressive symptoms would not be surprising as none of the patients from the present sample were diagnosed with dementia.

None of the studies from the domain of older person's mental health reviewed for the purpose of the present study implicated depression severity as a predictor of discrepancy between patient and informant reports of depressive symptomatology. However, depression severity was explored in a present study as there is some evidence in adult mental health literature that it was significantly associated with discrepancies between self- and clinician-rated depression (Carter, Frampton, Mulder, Luty, & Joyce, 2010). More relevant studies with elderly samples are needed to be able to put a non-significant result regarding depression severity into a meaningful perspective.

Location was included in analysis in order to account for any possible differences between MHC and Ward K2. The discrepancy between patient and informant reports of depressive symptomatology was predicted by location; discrepancy was greater for patients from the MHC day-hospital than for patients from Ward K2. This effect was only observed when depressive symptoms were assessed using CUDOS, and not when using the GDS-15. It is possible that greater discrepancy in depressive reports on CUDOS observed in MHC was due to an interplay between the ambiguity of the GDS-15 and differences between the samples in the patterns of presenting symptoms, such as the greater prevalence of anxiety in the day-hospital setting and the higher prevalence of the more easily differentiated psychosis in the inpatient setting.

#### 4.2.3 Discrepancy and informant's characteristics.

It was proposed that the discrepancy between self- and informant-reported symptoms of depression would be greater for male and non-partner informants. However, neither informant's gender nor relationship to the patient predicted this discrepancy.

The majority of studies did not include informant's gender or type of relationship to the patient as predictors of discrepancy in reports of depressive symptoms and those that did

found mixed results. Burke et al. (1998) did not find any significant associations between type of relationship between patient and informant, and the magnitude of discrepancy between their reports of depressive symptoms. The type of the relationship predicted the discrepancy in reports in studies by Bassett et al. (1990) and Cacchione et al. (2003). However, Cacchione et al. (2003) was not concerned with a comparison of depressive symptoms, but instead compared reports of patient's cognitive functioning.

The only study that found informant's gender as having a significant effect on differences between informant and older individual ratings was a study by Bassett et al. (1990) and their sample was comprised entirely of women. Thus, it is possible that the significant effect for informant's gender could to some extent reflect gender homogeneity of the initial sample and would not be observed if the sample included both sexes. This notion is to some extent supported by a study by McAvay et al. (2004) comprised of both men and women, in which they found a lack of significant effects of informant's gender on differences in ratings.

#### 4.2.5 Discrepancy for individual items

Overall, rates of agreement were mostly fair on the GDS-15 and slightly on the CUDOS. The highest kappa agreement was moderate and it was obtained only on three GDS-15 items and two CUDOS items. The content of these items related to feelings of worthlessness and life satisfaction on the GDS-15, and suicidal ideation and intent on the CUDOS. These results are rather unexpected and contrary to the hypothesis of the present study. It was expected that rates of agreement would be higher on items that refer to symptoms with clear behavioural manifestation (e.g. changes in appetite, sleep patterns and energy levels) than on items that referred to intrapsychic symptoms (e.g. feelings of guilt and worthlessness). These hypotheses were mostly based on a study by McDade-Montez et al. (2008) which supported a visibility effect and concluded that items used in assessment with informants should be

selected on the basis of their easiness to rate. However, support for a visibility effect does not exclude a possibility that some items might be perceived as difficult to rate while the informant might have an appropriate knowledge to rate them with reasonable accuracy. Findings of the present study are likely to support this rationale. McDade-Montez et al. (2008) reported that suicidality was perceived as the most difficult to rate and wellbeing moderately difficult whereas the current study observed the highest agreement on items assessing suicidality and to some extent wellbeing. Moreover, a study by McAvay et al. (2005) also observed that the agreement was the highest for suicidal symptoms, slightly less so for psychological symptoms of depression, and the lowest for somatic symptoms. This may be especially so with suicidality, as it is possible that due to high saliency of these symptoms they are perceived as difficult to rate, while at the same time family informants are highly invested to identify them correctly. A recent study from the adult mental health literature found moderate to high agreements on suicide symptoms between adult psychiatric inpatients with depression and their family informants (DeJong & Overholser, 2009). This further suggests that family informants may be capable of providing useful information about patient's suicidality.

In summary, even if present findings were somewhat unexpected it appears that they are to some extent consistent with findings from other studies in the mental health literature. However, it is important to note that overall kappa agreement between patient and informant on specific items was only slight to fair. In addition even on those few items where kappa agreement was moderate confidence intervals overlapped with other items on which agreement was fair or slight. Thus, it is questionable to what extent different levels of agreement on specific items are truly distinct and consequently to what extent that difference has any practical meaning.

## 4.4 Strengths and Limitations

### 4.4.1 Strengths.

The present study has a number of important strengths. Firstly, it was conducted in a real-life setting with an involvement of patient's clinicians (assistance in recruitment process and completion of HoNOS 65+). This allowed for an insight into practicality of using self-report measure in a psychogeriatric setting, which will be further discussed in the limitation section below.

Because of a fairly practical focus on the bigger project that the present study was part of, there was a strong commitment to include the majority of Ward K2 and MHC patients into the current investigation. Hence there were very few exclusion criteria and the research team put a lot of time and effort into obtaining self- and informant reports. This often involved several visits to the PMH regarding one patient and took a considerable amount of patience and persistence, as patients had several varying commitments as a part of their assessment and treatment at the hospital.

One of the other strengths of the present study was the oral form of administration of self-report questionnaires, which although took a longer time than using written format, was more comprehensive and allowed to clarify any questions or difficulties that patients had during the interview.

Another valuable point of the present study is inclusion of the CUDOS as one of the main measures. It is a relatively new instrument, and to the researcher's knowledge it has not been used with an older population. Thus, the current study was the first attempt to explore its use with a geriatric population.



#### 4.4.2 Limitations.

The present study also has some limitations worth acknowledging. One very apparent feature of the study was the low response rate. On the one hand, this could be acknowledged as a limitation of the study. However, this response rate in itself provides very interesting questions about the use of such measures and/or the feasibility of conducting this type of research in these settings. It was noted that the response rate for self-report was very poor on the inpatient ward as compared to the day-hospital. The Ward K2 patients were observed to be more unwell and distressed than the MHC patients. This could have had a negative impact on their ability to contemplate research participation or even fully comprehend an informed consent form. It was observed that several Ward K2 patients struggled with understanding the consent form and required greater assistance in completing it, through such means as using repetition or simpler language. In general, this was not the case at the MHC, and thus, it is not clear to what extent the low response rate at Ward K2 was negatively affected by the obligation to sign the consent form. It is possible that the response rate could have been higher if completing a self-report was a part of routine treatment planning.

Additionally, it was clearly observed that administration of self-report was often twice as long at the inpatient ward than at the day-hospital. There were several instances at Ward K2 where administration took over an hour, whereas there were no such instances at MHC. It was noted that prolonged administration time was often due to psychological distress observed among Ward K2 patients, and in consequence, somewhat reduced cognitive capacity to entirely focus on research questions for a distinct period of time. The Ward K2 patients were often very preoccupied with their admission and its impact on them and their families. There were several instances when patients could not focus their attention beyond intense rumination, anxious thoughts or delusions.

Obtaining self-report from older individuals can be valuable for a variety of reasons discussed previously. However, considering the low response rate and prolonged administration time it would be important to further investigate either possible ways of administering a self-report in as unthreatening and unburdensome way as possible, or to look at the overall feasibility of using self report in psychogeriatric inpatient settings.

It is also important to note that even for those patients who filled in the self-report in either setting, only a minority had informant questionnaires successfully collected. There were variety of reasons that this may have occurred, such as the patients not having anyone who they had regular and frequent contact with, or the patient feeling as a burden to their family and not wanting to further inconvenience them. The low response rate among informants puts in question the practicability of using informant data routinely in a clinical setting. Future research could further address this issue.

### 4.3 Implications of the Present Study

Implications of the present study are relevant to both clinical practice and research. First of all, the current study further confirms that clinicians should be cognizant of the fact that elderly patients and their family reports of depressive symptoms will differ to a considerable degree. Importantly, informants' seem to have a tendency to report more depressive symptoms than patients. It is impossible to determine the reasons behind this from the present study's findings, nevertheless it might warrant the need for different cut-off scores for patients and their informants. An awareness of this phenomenon can also help clinicians make sense of differences between patient and family reports of depressive symptoms.

The GDS-15 is considered the gold standard in the assessment of geriatric depression. However, discrepancy between patients and informant reports of depressive symptoms was greater when the GDS-15 was used. Importantly, there were several reservations noted around its validity. It appears that caution should be exercised when using the GDS-15 in both clinical practice and research. On the other hand, the CUDOS appears to be a useful measure, and more research into its use with this population is warranted.

It is likely that the differences between patient and family reports of depressive symptoms might be greater for male than for female elderly patients. There seems to be no simple explanation for these gender differences. Thus, it appears that clinicians confronted with them should carefully explore them on a case-by-case basis.

Further, family members may be a valuable source of information regarding older patients' suicide risk. They could potentially aid the risk assessment as they appear to be knowledgeable and to some extent accurate in predicting patient's suicide ideation and intent. It also appears that family and patient reports of somatic symptoms may be considerably different. As in the present study there was no gold standard, it is impossible to determine whose reports are closer to objective reality. A comparison of patient and family reports with an external measure of physical symptoms occurrence could assist in explaining these differences.

Interestingly, one of the observations while conducting the present study was that the feasibility of standard use of self-report questionnaires in assessment of psychogeriatric inpatients might be questionable. However, it should be further explored in future research.

## 4.5 Future Research

There are a few potential directions for future research that have been implicated through the findings of the present study. There appear to be gender differences in self-reported depressive symptomatology that increase discrepancy between self- and informant reports of these symptoms. Exploring the nature of these differences could improve diagnosis and treatment of depression in late life.

As previously mentioned, it would also be of interest to explore validity of the GDS-15. Although the GDS-15 has been designed to be specifically used with older people, its simplistic format, exclusion of depressed mood, suicidality, and somatic symptoms of depression as well as somewhat vaguely phrased questions, makes the exact nature of the construct being assessed questionable.

Examining further the rates of agreement between patient and family informant reports of specific depressive symptoms could have some interesting future implications. At present not many studies looked at this and findings of those that have are to some extent mixed. Family members are routinely involved in assessment and treatment of older individuals with mental health difficulties. Having a better understanding of how accurate they are in reporting specific symptoms of depression could assist clinicians in interpretation of common discrepancies between patient and family reports of these symptoms.

The use of informants may be of most use when the individual is unable or unwilling to complete a self-report. However, the present study does not necessarily indicate how closely this report would relate to the individuals report in these situations. Snow et al. (Snow, Cook, et al., 2005) defined and described two categories of externally rated data; proxy data and other-rated data. Proxy data referred to those collected from someone who speaks for a patient who cannot, will not, or is unavailable to speak for him or herself. The term other-

rated data referred to situations in which the researcher collects ratings from a person other than the patient to gain multiple perspectives on the assessed constructs. The authors proposed that these two types of data differ in the way the measurement model is defined, the definition of a gold standard against which the measurements are validated, the analysis strategies appropriately used, and how the analyses are interpreted. The method in which data was analysed and interpreted in the present study was consistent with other-rated data. The validity of proxy data is a gap that would benefit from future research. In terms of research that deals with external raters of older individuals with mental health difficulties, it would be prudent to clearly define whether a study will be dealing with proxy or other-rated data. To be able to make that choice in an informed way, a population of interest should be assessed in terms of their capacity to complete self-report prior to data collection.

As previously noted it would be interesting to investigate the practicality of using informant data routinely in psychogeriatric setting. Reasons behind low informant response rates could be examined in more detail, and ways to improve it could be explored in order to incorporate significant others perspective in a systematic and cost/time effective way.

Finally, it appears to be vital to further examine the feasibility of the use of self-report scales in the inpatient psychogeriatric setting. Future studies could possibly look at such factors as length of time that it take to administer self-report and how it may translate to the potential cost, impact of self-report on older individuals levels of distress, or accuracy of self reports. This could help to determine whether it is clinically practical as well as valid in terms of research to utilize self-report with older psychiatric inpatients.



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## APPENDIX A

### GLOSSARY OF MEDICAL TERMS

Alzheimer's Disease (AD) - is the most common form of dementia; it is an incurable, degenerative, and terminal disease. Most often, it is diagnosed in people over 65 years of age, although the less-prevalent early-onset Alzheimer's can occur much earlier. Although the course of Alzheimer's disease is unique for every individual, there are many common symptoms. The earliest observable symptoms are often mistakenly thought to be 'age-related' concerns, or manifestations of stress. In the early stages, the most commonly recognized symptom is inability to acquire new memories, such as difficulty in recalling recently observed facts. As the disease advances, symptoms include confusion, irritability and aggression, mood swings, language breakdown, long-term memory loss, and the general withdrawal of the sufferer as their senses decline. Gradually, bodily functions are lost, ultimately leading to death. Individual prognosis is difficult to assess, as the duration of the disease varies. AD develops for an indeterminate period of time before becoming fully apparent, and it can progress undiagnosed for years. The mean life expectancy following diagnosis is approximately seven years.

Haematoma - is an extravasation of blood outside the blood vessels, generally the result of hemorrhage. A hematoma is a pocket or localized collection of blood usually in liquid form within the tissue.

Hyperparathyroidism - is overactivity of the parathyroid glands resulting in excess production of parathyroid hormone (PTH). The parathyroid hormone regulates calcium and phosphate levels and helps to maintain these levels. Excessive PTH secretion may be due to problems in the glands themselves, in which case it is referred to as *primary*

hyperparathyroidism and which leads to hypercalcemia (raised calcium levels). It may also occur in response to low calcium levels, as encountered in various situations such as vitamin D deficiency or chronic kidney disease; this is referred to as secondary hyperparathyroidism. In all cases, the raised PTH levels are harmful to bone, and treatment is often needed.

Hypothyroidism - is a deficiency of thyroid hormone. Iodine deficiency is the most common cause of hypothyroidism worldwide but it can be caused by any number of other causes such as several conditions of the thyroid gland, or less commonly, the pituitary gland or hypothalamus. Early hypothyroidism has often very mild and unspecific symptoms. Hypothyroidism can be associated with the following symptoms; poor muscle tone, fatigue, any form of menstrual irregularity and fertility problems, elevated serum cholesterol, cold intolerance, increased sensitivity to cold, constipation, depression, muscle cramps, joint pains, dry and itchy skin, weight gain, and others.



Myocardial Infarction - commonly known as a heart attack, is the interruption of blood supply to a part of the heart, causing heart cells to die. This is most commonly due to occlusion (blockage) of a coronary artery following the rupture of a vulnerable atherosclerotic plaque which is an unstable collection of lipids and white blood cells in the wall of an artery. The resulting ischemia (restriction in blood supply) and oxygen shortage, if left untreated for a sufficient period of time, can cause damage or death (infarction) of heart muscle tissue (myocardium).

Pancreatic Cancer - is a malignant neoplasm of the pancreas. It is estimated that in 2010 more than 43,000 individuals in the United States have been diagnosed with this condition, and 36,800 have died from the disease. The prognosis is poor, with fewer than 5% of those diagnosed still alive five years after diagnosis. Complete remission is still rare.

Parkinson's Disease (PD) - is a progressive degenerative disorder of the central nervous system. Early in the course of the disease, the most obvious symptoms are movement-related, including shaking, rigidity, slowness of movement, and difficulty with walking and gait. Later, cognitive and behavioral problems may arise, with dementia commonly occurring in the advanced stages of the disease. Other symptoms include sensory, sleep and emotional problems. PD typically becomes apparent around the age of 60 years and is unusual before the age of 40 years.

Vascular Dementia - is the second most common form of dementia after (AD) in older adults; is thought to be an irreversible form of dementia, and its onset is caused by a number of small strokes or sometimes, one large stroke. The term refers to a group of syndromes caused by different mechanisms all resulting in vascular lesions in the brain. Early detection and accurate diagnosis are important, as vascular dementia is at least partially preventable.

## APPENDIX B PATIENT'S STUDY INFORMATION SHEET

<div style="text-align: center;">  <p><b>Psychiatry of Old Age</b> Academic Unit</p> </div> <div style="text-align: center; border: 1px solid black; padding: 5px; margin-top: 10px;"> <p><b>Research Invitation</b></p> </div>	<div style="text-align: center; margin-bottom: 20px;"> <p><b>Outcome Questionnaires</b></p>  </div> <div style="display: flex; justify-content: space-between; align-items: center;"> <div style="width: 60%;"> <p><b>To contact us</b></p> <p>If you have any questions please feel free to contact Kasia.</p> <p>You can call her on (03) 376 4510 Or 021 057 1940</p> <p>The study is being supervised by Dr Matthew Croucher (Consultant Psychiatrist) Susan Gee, PhD (Research Associate)</p> <p>Psychiatric Services for the Elderly Princess Margaret Hospital PO Box 800 Christchurch Tel: 337 8894</p> <p>and Neville Blampeid, PhD Canterbury University (03) 364 2199</p> </div> <div style="width: 35%; text-align: center;"> <p><b>Canterbury</b> District Health Board <small>Te Poari Hauora o Waitaha</small></p> </div> </div>
<p><b>It is your choice</b></p> <p>You do not have to take part in this study, the choice is up to you. If you would like to take part, we would appreciate your help.</p> <p>If you would rather not take part that is fine.</p> <p>You can change your mind at anytime and withdraw from the study.</p> <p>Choosing not to take part, or withdrawing from the study, will in no way affect your health care now or in the future.</p> <p>Please take your time to think about whether you would like to take part. You may like to talk it over with someone close to you. Feel free to ask any questions. Our contact details are on the back page.</p> <p>If you would like the help of an interpreter or the Maori Mental Health Worker, just let us know.</p>	<div style="text-align: center; margin-bottom: 20px;"> <p><b>Canterbury</b> District Health Board <small>Te Poari Hauora o Waitaha</small></p> </div>

## A RESEARCH INVITATION

### What are outcome measures?

Outcome measures are questionnaires that gather information about you. They ask about how you are feeling and coping with usual life activities.

Some questionnaires are completed by the staff and some are completed by you.

The questionnaires help staff to better understand your progress and address your needs.



### What is the study about?

This study looks at what is the best outcome measure to use. It also looks at whether it is useful to ask someone close to a patient to complete the questionnaires for them. This is a very important question because sometimes patients may be unable to complete a questionnaire.

We would like to compare the answers given by people who are admitted to Ward K2 to the outcome questionnaires with the answers given by someone close to them. This person might be a spouse/partner, family member, or friend.

This research will be conducted by Kasia Madrzejewska. She is a psychology student completing her masters degree at the University of Canterbury.

### What would be involved?

Kasia will visit you on the ward to see if you would like to take part. If you would like to help, you will be given two questionnaires about how you are feeling and coping. Many people will complete these both in less than ten minutes. We will give them again when you are discharged to see how things have changed.

You can also suggest a person close to you for Kasia to contact. Kasia would give them the two questionnaires to see how they think you are feeling and coping. She will only contact someone close to you if you say it is ok.

We will compare the answers from the patients with those given by friends and family. We will only include the answers in your patient notes if you say it is ok to do so. When we write up the research we won't ever use your name.

APPENDIX C  
GERIATRIC DEPRESSION SCALE 15-ITEM VERSION (GDS-15)

MOOD SCALE

Choose the best answer for how you have felt over the past week:

- |   |          |
|---|----------|
| 1. Are you basically satisfied with your life? .....                                | YES / NO |
| 2. Have you dropped many of your activities and interests? .....                    | YES / NO |
| 3. Do you feel that your life is empty? .....                                       | YES / NO |
| 4. Do you often get bored? .....  | YES / NO |
| 5. Are you in good spirits most of the time? .....                                  | YES / NO |
| 6. Are you afraid that something bad is going to happen to you? .....               | YES / NO |
| 7. Do you feel happy most of the time? .....  | YES / NO |
| 8. Do you often feel helpless? .....  | YES / NO |
| 9. Do you prefer to stay at home, rather than going out and doing new things? ..... | YES / NO |
| 10. Do you feel you have more problems with memory than most? .....                 | YES / NO |
| 11. Do you think it is wonderful to be alive now? .....                             | YES / NO |
| 12. Do you feel pretty worthless the way you are now? .....                         | YES / NO |
| 13. Do you feel full of energy? .....   | YES / NO |
| 14. Do you feel that your situation is hopeless? .....                              | YES / NO |
| 15. Do you think that most people are better off than you are? .....                | YES / NO |

APPENDIX D  
INFORMANT VERSION OF THE GDS-15

MOOD SCALE

Choose the best answer for how \_\_\_\_\_ has felt over the past week:

1. Are they basically satisfied with their life? ..... YES / NO
2. Have they dropped many of their activities and interests? .....YES / NO
3. Do they feel that their life is empty? ..... YES / NO
4. Do they often get bored? ..... YES / NO
5. Are they in good spirits most of the time? ..... YES / NO
6. Are they afraid that something bad is going to happen to them? ..... YES / NO
7. Do they feel happy most of the time? ..... YES / NO
8. Do they often feel helpless? ..... YES / NO
9. Do they prefer to stay at home, rather than going out and doing new things? .....YES / NO
10. Do they feel they have more problems with memory than most? ..... YES / NO
11. Do they think it is wonderful to be alive now? ..... YES / NO
12. Do they feel pretty worthless the way they are now? ..... YES / NO
13. Do they feel full of energy? ..... YES / NO
14. Do they feel that their situation is hopeless? ..... YES / NO
15. Do they think that most people are better off than they are? ..... YES / NO



## APPENDIX E

### CLINICALLY USEFUL DEPRESSION OUTCOME SCALE (CUDOS)

#### Instructions

This questionnaire includes questions about symptoms of depression. For each item, please indicate how well it describes you during the past week, including today. Circle the number in the columns next to the item that best describes you.

#### Rating Guidelines

0=not at all true (0 days)

1=rarely true (1–2 days)

2=sometimes true (3–4 days)

3=often true (5–6 days)

4=almost always true (every day)

During the **past week, including today...**

- |   |   |   |   |   |   |
|---|---|---|---|---|---|
| 1. I felt sad or depressed. ....                                      | 0 | 1 | 2 | 3 | 4 |
| 2. I was not as interested in my usual activities. ....               | 0 | 1 | 2 | 3 | 4 |
| 3. My appetite was poor, and I didn't feel like eating. ....          | 0 | 1 | 2 | 3 | 4 |
| 4. My appetite was much greater than usual. ....                      | 0 | 1 | 2 | 3 | 4 |
| 5. I had difficulty sleeping. ....                                    | 0 | 1 | 2 | 3 | 4 |
| 6. I was sleeping too much. ....                                      | 0 | 1 | 2 | 3 | 4 |
| 7. I felt very fidgety, making it difficult to sit still. ....        | 0 | 1 | 2 | 3 | 4 |
| 8. I felt physically slowed down, like my body was stuck in mud. .... | 0 | 1 | 2 | 3 | 4 |
| 9. My energy level was low. ....                                      | 0 | 1 | 2 | 3 | 4 |
| 10. I felt guilty. ....   | 0 | 1 | 2 | 3 | 4 |
| 11. I thought I was a failure. ....                                   | 0 | 1 | 2 | 3 | 4 |
| 12. I had problems concentrating. ....                                | 0 | 1 | 2 | 3 | 4 |
| 13. I had more difficulties making decisions than usual. ....         | 0 | 1 | 2 | 3 | 4 |
| 14. I wished I was dead. ....   | 0 | 1 | 2 | 3 | 4 |
| 15. I thought about killing myself. ....                              | 0 | 1 | 2 | 3 | 4 |
| 16. I thought that the future looked hopeless. ....                   | 0 | 1 | 2 | 3 | 4 |

17. Overall, how much have symptoms of depression interfered with or caused difficulties in your life during the past week?

- 0) not at all
- 1) a little bit
- 2) a moderate amount
- 3) quite a bit
- 4) extremely

18. How would you rate your overall quality of life during the past week?

- 0) very good; my life could hardly be better
- 1) pretty good; most things are going well
- 2) the good and bad parts are about equal
- 3) pretty bad; most things are going poorly
- 4) very bad; my life could hardly be worse

## APPENDIX F

### INFORMANT VERSION OF THE CUDOS (CUDOS-I)

#### Instructions

This questionnaire includes questions about symptoms of depression. For each item, please indicate how well it describes \_\_\_\_\_ during the past week, including today. Circle the number in the columns next to the item that best describes them.

#### Rating Guidelines

0=not at all true (0 days)

1=rarely true (1–2 days)

2=sometimes true (3–4 days)

3=often true (5–6 days)

4=almost always true (every day)

During the **past week, including today...**

- |   |   |   |   |   |   |
|---|---|---|---|---|---|
| 1. They felt sad or depressed. ....   | 0 | 1 | 2 | 3 | 4 |
| 2. They were not as interested in their usual activities. ....              | 0 | 1 | 2 | 3 | 4 |
| 3. Their appetite was poor, and they didn't feel like eating. ....          | 0 | 1 | 2 | 3 | 4 |
| 4. Their appetite was much greater than usual. ....                         | 0 | 1 | 2 | 3 | 4 |
| 5. They had difficulty sleeping. ....                                       | 0 | 1 | 2 | 3 | 4 |
| 6. They were sleeping too much. ....  | 0 | 1 | 2 | 3 | 4 |
| 7. They felt very fidgety, making it difficult to sit still. ....           | 0 | 1 | 2 | 3 | 4 |
| 8. They felt physically slowed down, like their body was stuck in mud. .... | 0 | 1 | 2 | 3 | 4 |
| 9. Their energy level was low. ....   | 0 | 1 | 2 | 3 | 4 |
| 10. They felt guilty. ....  | 0 | 1 | 2 | 3 | 4 |
| 11. They thought they were a failure. ....                                  | 0 | 1 | 2 | 3 | 4 |
| 12. They had problems concentrating. ....                                   | 0 | 1 | 2 | 3 | 4 |
| 13. They had more difficulties making decisions than usual. ....            | 0 | 1 | 2 | 3 | 4 |
| 14. They wished they were dead. ....  | 0 | 1 | 2 | 3 | 4 |
| 15. They thought about killing themselves. ....                             | 0 | 1 | 2 | 3 | 4 |
| 16. They thought that the future looked hopeless. ....                      | 0 | 1 | 2 | 3 | 4 |

17. Overall, how much have symptoms of depression interfered with or caused difficulties in their life during the past week?

- 0) not at all
- 1) a little bit
- 2) a moderate amount
- 3) quite a bit
- 4) extremely

18. How would you rate their overall quality of life during the past week?

- 0) very good; their life could hardly be better
- 1) pretty good; most things are going well
- 2) the good and bad parts are about equal
- 3) pretty bad; most things are going poorly
- 4) very bad; their life could hardly be worse

## APPENDIX G

### HEALTH OF THE NATION OUTCOME SCALE 65+ (HoNOS 65+)

#### *General rating guidelines*

##### *Note:*

*Staff enter the ratings online onto the Canterbury District Health Board system.*

*The HoNOS is a mandated assessment measure and will be rated regardless of participation in the research study*

- Perform a full clinical assessment of the patient's clinical history and current problems
- Rate items in order from 1 to 12.
- Do not include information already rated in an earlier item.
- Rate the most severe problem that occurred in the period rated.
- The rating period is generally the preceding two weeks for inpatients at admission, for hospital outpatients, and for all clients of community-based services. The exception is at discharge from acute inpatient care, in which case the rating period should generally be the preceding 72 hours.
- Each item is rated on a 5-point scale of severity (0 to 4) as follows:
  0. No problem
  1. Minor problem requiring no formal action
  2. Mild problem. Should be recorded in a care plan or other case record
  3. Problem of moderate severity
  4. Severe to very severe problem
  7. Not known / Unable to rate.
- Specific help for rating each point on each item is provided in the Glossary.
- As far as possible, the use of rating point 7 should be avoided, because missing data make scores less comparable over time or between settings.

#### *HoNOS65+ scores: Clinical significance and recommended actions*

<b>Not clinically significant</b>	0	No problem	Problem not present.
	1	Minor problem	Requires no formal action. May or may not be recorded in clinical file.
<b>Clinically significant</b>	2	Mild problem	Warrants recording in clinical file. May or may not be incorporated in care plan.
	3	Moderate problem	Warrants recording in clinical file. Should be incorporated in care plan.
	4	Severe to very severe problem	Most severe category for patients with this problem. Warrants recording in clinical file. Should be incorporated in care plan. Note: Patient can get worse.

### *HoNOS65+ glossary*

1. Behavioural disturbance (eg. overactive, aggressive, disruptive or agitated behaviour, uncooperative or resistive behaviour)

Include such behaviour due to any cause, eg. dementia, drugs, alcohol, psychosis, depression, etc.

Do not include bizarre behaviour, rated at Scale 6.

0. No problems of this kind during the period rated.

1. Occasional irritability, quarrels, restlessness etc., but generally calm and co-operative and not requiring any specific action.
2. Includes aggressive gestures, pushing or pestering others; threats or verbal aggression; lesser damage to property (e.g. broken cup, window); significant overactivity or agitation; intermittent restlessness or wandering (day or night); uncooperative at times, requiring encouragement and persuasion.
3. Physically aggressive to others or animals (short of rating 4); more serious damage to, or destruction of, property; frequently threatening manner, more serious or persistent overactivity or agitation; frequent restlessness or wandering; significant problems with co-operation, largely resistant to help or assistance.
4. At least one serious physical attack on others (over and above rating of 3); major or persistent destructive activity (e.g. fire-setting); persistent and threatening behaviour; severe overactivity or agitation; sexually disinhibited or other inappropriate behaviour (e.g. deliberate inappropriate urination or defecation); virtually constant restlessness or wandering; severe problems related to non-compliant or resistive behaviour.

### 2. Non-accidental self-injury

Do not include *accidental* self-injury (due eg. to dementia or severe learning disability); any cognitive problem is rated at Scale 4 and the injury at Scale 5.

Do not include illness or injury as a direct consequence of drug or alcohol use rated at Scale 3, (eg. cirrhosis of the liver or injury resulting from drunk-driving are rated at Scale 5).

0. No problem of this kind during the period rated.

1. Fleeting thoughts of self-harm or suicide; but little or no risk during the period rated.
2. Mild risk during period; includes more frequent thoughts or talking about self-harm or

suicide (including 'passive' ideas of self-harm such as not taking avoiding action in a potentially life-threatening situation, eg. while crossing a road).

3. Moderate to serious risk of deliberate self-harm during the period rated; includes frequent or persistent thoughts or talking about self-harm; includes preparatory behaviours, eg. collecting tablets.
4. Suicidal attempt or deliberate self-injury during period.

### 3. Problem drinking or drug-taking

*Do not include aggressive or destructive behaviour due to alcohol or drug use, rated at Scale 1.*

*Do not include physical illness or disability due to alcohol or drug use, rated at Scale 5.*

0. No problem of this kind during the period rated.
1. Some over-indulgence but within social norm.
2. Occasional loss of control of drinking or drug-taking; but not a serious problem.
3. Marked craving or dependence on alcohol or drug use with frequent loss of control, drunkenness, etc.
4. Major adverse consequences or incapacitated due to alcohol or drug problems.

### 4. Cognitive problems

*Include problems of orientation, memory, and language associated with any disorder: dementia, learning disability, schizophrenia, etc.*

*Do not include temporary problems (eg. hangovers) which are clearly associated with alcohol, drug or medication use, rated at Scale 3.*

0. No problem of this kind during the period rated.
1. Minor problems with orientation (eg. some difficulty with orientation to time) or memory (eg. a degree of forgetfulness but still able to learn new information), no apparent difficulties with the use of language.
2. Mild problems with orientation (eg. frequently disorientated to time) or memory (eg. definite problems learning new information such as names, recollection of recent events;

deficit interferes with everyday activities); difficulty finding way in new or unfamiliar surroundings; able to deal with simple verbal information but some difficulties with understanding or expression of more complex language.

3. Moderate problems with orientation (eg. usually disorientated to time, often place) or memory (eg. new material rapidly lost, only highly learned material retained, occasional failure to recognise familiar individuals); has lost the way in a familiar place; major difficulties with language (expressive or receptive).
4. Severe disorientation (eg. consistently disorientated to time and place, and sometimes to person) or memory impairment (eg. only fragments remain, loss of distant as well as recent information, unable to effectively learn any new information, consistently unable to recognise or to name close friends or relatives); no effective communication possible through language or inaccessible to speech.

## 5. Physical illness or disability problems

*Include illness or disability from any cause that limits mobility, impairs sight or hearing, or otherwise interferes with personal functioning (eg. pain).*

*Include side-effects from medication; effects of drug/alcohol use; physical disabilities resulting from accidents or self-harm associated with cognitive problems, drunk driving etc.*

*Do not include mental or behavioural problems rated at Scale 4.*

0. No physical health, disability or mobility problems during the period rated.
1. Minor health problem during the period (e.g. cold); some impairment of sight or hearing (but still able to function effectively with the aid of glasses or hearing aid).
2. Physical health problem associated with mild restriction of activities or mobility (e.g. restricted walking distance, some degree of loss of independence); moderate impairment of sight or hearing (with functional impairment despite the appropriate use of glasses or hearing aid); some degree of risk of falling, but low and no episodes to date; problems associated with mild degree of pain.
3. Physical health problem associated with moderate restriction of activities or mobility (e.g. mobile only with an aid - stick or Zimmer frame - or with help); more severe impairment of sight or hearing (short of rating 4); significant risk of falling (one or more falls); problems associated with a moderate degree of pain.
4. Major physical health problem associated with severe restriction of activities or mobility (e.g. chair or bed bound); severe impairment of sight or hearing (e.g. registered blind or deaf); high risk of falling (one or more falls) because of physical illness or disability;



problems associated with severe pain; presence of impaired level of consciousness.

## 6. Problems associated with hallucinations and delusions

*Include hallucinations and delusions (or false beliefs) irrespective of diagnosis.*

*Include odd and bizarre behaviour associated with hallucinations or delusions (or false beliefs).*

*Do not include aggressive, destructive or overactive behaviours attributed to hallucinations, delusions or false beliefs, rated at Scale 1.*

0. No evidence of delusions or hallucinations during the period rated.
1. Somewhat odd or eccentric beliefs not in keeping with cultural norms.
2. Delusions or hallucinations (eg. voices, visions) are present, but there is little distress to consumer or manifestation in bizarre behaviour, that is, a present, but mild clinical problem.
3. Marked preoccupation with delusions or hallucinations, causing significant distress or manifested in obviously bizarre behaviour, that is, moderately severe clinical problem.
4. Mental state and behaviour is seriously and adversely affected by delusions or hallucinations, with a major impact on consumer or others.

## 7. Problems with depressive symptoms

*Do not include overactivity or agitation, rated at Scale 1.*

*Do not include suicidal ideation or attempts, rated at Scale 2.*

*Do not include delusions or hallucinations, rated at Scale 6.*

*Rate associated problems (eg. changes in sleep, appetite or weight; anxiety symptoms) at Scale 8.*

0. No problems associated with depression during the period rated.
1. Gloomy; or minor changes in mood only.

2. Mild but definite depression on subjective or objective measures (eg. loss of interest or pleasure, lack of energy, loss of self-esteem, feelings of guilt).
3. Moderate depression on subjective or objective measures (depressive symptoms more marked).
4. Severe depression on subjective or objective grounds (eg. profound loss of interest or pleasure, preoccupation with ideas of guilt or worthlessness).

## 8. Other mental and behavioural problems

*Rate only the most severe clinical problem not considered at Scales 6 and 7 as follows: specify the type of problem by entering the appropriate letter: A phobic; B anxiety; C obsessive-compulsive; D stress; E dissociative; F somatoform; G eating; H sleep; I sexual; J other, specify.*

0. No evidence of any of these problems during period rated.
1. Minor non-clinical problems.
2. A problem is clinically present, but at a mild level, for example the problem is intermittent, the consumer maintains a degree of control or is not unduly distressed.
3. Moderately severe clinical problem, for example, more frequent, more distressing or more marked symptoms.
4. Severe persistent problems that dominates or seriously affects most activities.

## 9. Problems with relationships

*Problems associated with social relationships, identified by the consumer or apparent to carers or others. Rate the consumer's most severe problem associated with active or passive withdrawal from, or tendency to dominate, social relationships or non-supportive, destructive or self-damaging relationships.*

0. No significant problems during the period.
1. Minor non-clinical problems.
2. Definite problems in making, sustaining or adapting to supportive relationships (eg. because of controlling manner, or arising out of difficult, exploitative or abusive

relationships), definite but mild difficulties reported by consumer or evident to carers or others.

3. Persisting significant problems with relationships; moderately severe conflicts or problems identified within the relationship by the consumer or evident to carers or others.
4. Severe difficulties associated with social relationships (eg. isolation, withdrawal, conflict, abuse); major tensions and stresses (eg. threatening breaking down of relationship).

## 10. Problems with activities of daily living

*Rate the overall level of functioning in activities of daily living (ADL): eg. problems with basic activities of self-care such as eating, washing, dressing, toilet; also complex skills such as budgeting, recreation and use of transport, etc.*

*Include any lack of motivation for using self-help opportunities, since this contributes to a lower overall level of functioning.*

*Do not include lack of opportunities for exercising intact abilities and skills, rated at Scales 11 and Scale 12.*

0. No problems during period rated; good ability to function effectively in all basic activities (eg. continent - or able to manage incontinence appropriately, able to feed self and dress) and complex skills (eg. driving or able to make use of transport facilities, able to handle financial affairs appropriately).
1. Minor problems only without significantly adverse consequences, for example, untidy, mildly disorganised, some evidence to suggest minor difficulty with complex skills but still able to cope effectively.
2. Self-care and basic activities adequate (though some prompting may be required), but difficulty with more complex skills (eg. problem organising and making a drink or meal, deterioration in personal interest especially outside the home situation, problems with driving, transport or financial judgements).
3. Problems evident in one or more areas of self-care activities (eg. needs some supervision with dressing and eating, occasional urinary incontinence or continent only if toileted) as well as inability to perform several complex skills.
4. Severe disability or incapacity in all or nearly all areas of basic and complex skills (eg. full supervision required with dressing and eating, frequent urinary or faecal incontinence).

## 11. Problems with living conditions

*Rate the overall severity of problems with the quality of living conditions, accommodation and daily domestic routine, taking into account the consumer's preferences and degree of satisfaction with circumstances.*

*Are the basic necessities met (heat, light, hygiene)? If so, does the physical environment contribute to maximising independence and minimising risk, and provide a choice of opportunities to facilitate the use of existing skills and develop new ones?*

*Do not rate the level of functional disability itself, rated at Scale 10.*

*NB: Rate consumer's usual accommodation. If in acute ward, rate the home accommodation. If information not obtainable, rate 7.*

0. Accommodation and living conditions are acceptable; helpful in keeping any disability rated at Scale 10 to the lowest level possible and minimising any risk, and supportive of self-help; the consumer is satisfied with their accommodation.
1. Accommodation is reasonably acceptable with only minor or transient problems related primarily to the consumer's preferences rather than any significant problems or risks associated with their environment (eg. not ideal location, not preferred option, doesn't like food).
2. Basics are met but significant problems with one or more aspects of the accommodation or regime (eg. lack of proper adaptation to optimise function relating for instance to stairs, lifts or other problems of access); may be associated with risk to consumer (eg. injury) which would otherwise be reduced.
3. Distressing multiple problems with accommodation; eg. some basic necessities are absent (unsatisfactory or unreliable heating, lack of proper cooking facilities, inadequate sanitation); clear elements of risk to the consumer resulting from aspects of the physical environment.
4. Accommodation is unacceptable: eg. lack of basic necessities, insecure, or living conditions are otherwise intolerable, contributing adversely to the consumer's condition or placing them at high risk of injury or other adverse consequences.

## 12. Problems with occupation and activities

*Rate the overall level of problems with quality of day-time environment. Is there help to cope with disabilities, and opportunities for maintaining or improving occupational and recreational skills and activities? Consider factors such as stigma, lack of qualified staff, lack of access to supportive facilities, eg. staffing and equipment of day centres, social clubs, etc.*

*Do not rate the level of functional disability itself, rated at Scale 10.*

*NB: Rate the consumer's usual situation. If in acute ward, rate activities during period before admission. If information not available, rate 7.*

0. Consumer's day-time environment is acceptable; helpful in keeping any disability rated at Scale 10 to the lowest level possible, and maximising autonomy.
1. Minor or temporary problems, eg. good facilities available but not always at appropriate times for the consumer.
2. Limited choice of activities; e.g. insufficient carer or professional support, useful day setting available but for very limited hours.
3. Marked deficiency in skilled services and support available to help optimise activity level and autonomy, little opportunity to use skills or to develop new ones; unskilled care difficult to access.
4. Lack of any effective opportunity for daytime activities makes the consumer's problems worse or consumer refuses services offered which might improve their situation.

#### Important variations in rating guidelines

	Core rules	
Scale	Rate the worst manifestation	Rate over the past two weeks
Scales 1-8	Always	Always
Scales 9, 10	Based on usual or typical	Always
Scales 11, 12	Based on usual or typical	May need to go back beyond two weeks to establish the usual situation

## APPENDIX H CONSENT FORM

### Consent form for participants

Getting better: Evaluating outcome measures for depression in older people in mental health services

I, ..... (name)  
have read the participant information sheet for this study and I understand it.

I understand that I do not have to take part in this study, it is my choice. I can withdraw at any time. This will not affect my health care in anyway. I do not have to answer any questions that I don't want to.

Taking part in the study involves completing two questionnaires about how I am feeling and coping. The two questionnaires are each only a single page long.

I am willing to answer the questionnaires      YES / NO

The questionnaire will only be added to my patient notes if I say that it is ok.

I would like my completed questionnaires

to be put in my patient notes      YES / NO

I can also help by suggesting a person close to me that a researcher would contact. The researcher will invite them to complete the questionnaires about how they think I am feeling and coping.

I am willing to suggest someone, and for the

researcher to invite them to take part      YES / NO

The researchers will offer the same questionnaires when I am about to be discharged from Ward K2, to see how things have changed. I can decide then whether I want to complete them and whether it is ok for researchers to contact someone close to me again.

I would like to be sent a summary of the results

in mid 2010      YES / NO

I understand that my answers in the study are confidential and that no materials that might identify me will be used in any reports on this study.

Before signing this form, I have had the opportunity to discuss the study with one of the researchers and to ask any questions about this study. I know that I am welcome to have whanau or family support or a friend to help me ask questions and understand the study. I have had enough time to consider my decision to take part.

I ..... (full name) hereby agree to participate in this study.

SIGNATURE: .....

DATE: .....

I, ..... (researcher) confirm that I have explained the nature and purpose of this study to the participant whose name is printed above.

RESEARCHER SIGNATURE:

.....

DATE: .....

## Consent form for informants

Getting better: Evaluating outcome measures for depression in older people in mental health services

I..... (name)

have read the participant information sheet for this study and I understand it.

I understand that I do not have to take part in this study, it is my choice. I can withdraw at any time. This will not affect my health care in anyway. I do not have to answer any questions that I don't want to.

Taking part in the study involves completing two questionnaires about how \_\_\_\_\_ is feeling and coping. The two questionnaires are each only a single page long.

The researchers will offer the same questionnaires when \_\_\_\_\_ is about to be discharged from Ward K2, to see how things have changed. I can decide then whether I want to complete them.

I would like to be sent a summary of the results

in mid 2010

YES / NO

I understand that my answers in the study are confidential and that no materials that might identify me will be used in any reports on this study.



Before signing this form, I have had the opportunity to discuss the study with one of the researchers and to ask any questions about this study. I know that I am welcome to have whanau or family support or a friend to help me ask questions and understand the study. I have had enough time to consider my decision to take part.

I ..... (full name) hereby agree to participate in this study.

SIGNATURE: .....

DATE: .....

I, .....(researcher) confirm that I have explained the nature and purpose of this study to the participant whose name is printed above.

RESEARCHER SIGNATURE:.....

DATE: .....

A signed copy of this document must be given to the informant.

## APPENDIX I

### INFORMANT'S STUDY INFORMATION SHEET

Getting better: Evaluating outcome measures for depression in older people in mental health services

Information for friends and family

Principal researchers:

Katarzyna (Kasia) Madrzejewska, Masters Student

Matthew Croucher, Consultant Psychiatrist

Susan Gee, Research Associate

Psychiatry Service for the Elderly

Princess Margaret Hospital

PO BOX 731

Christchurch 8022

Tel: 03 337 8894

You are invited to take part in our study looking at how we can best measure how people are feeling and coping, and whether they are getting better.

You do not have to take part in this study, it is your choice.

Please read these pages to find out more about the study before you make up your mind.

Please take your time to think about whether you would like to take part. You may like to talk it over with someone close to you. Feel free to ask any questions.

## About the study

This study looks at what is the best outcome measure to use. It also looks at whether it is useful to ask someone close to a patient to complete the questionnaires for them. This is a very important question because sometimes patients may be unable to complete a questionnaire.

We would like to compare the answers given by people who are admitted to Ward K2 to the outcome questionnaires with the answers given by someone close to them.

\_\_\_\_\_ has completed these questionnaires, and they suggested you as a person close to them.

- ◆ The study is open to anyone suggested by a person admitted to Ward K2 who is able to complete the questionnaires.
- ◆ The study will involve up to 120 people. We will be conducting the study from April 2009 to June 2010.

If you would like to take part in the study, you will complete two questionnaires.

- ◆ The questionnaires will ask how \_\_\_\_\_ is feeling and how they are coping with their usual life activities.
- ◆ The two questionnaires are each only a single page long.
- ◆ Just let us know if you would like the support of the Maori Mental Health Worker, or would like the help of an interpreter.
- ◆ We will offer the same questionnaires to you again when \_\_\_\_\_ is about to be discharged to see how things have changed.

This research will be conducted by Kasia Madrzejewska. She is a psychology student completing her masters degree at the university of Canterbury.

- ◆ Kasia will contact you to see if you interested in taking part.
- ◆ She will check what would be most convenient for you – to fill out the questionnaires yourself, to answer the questions over the phone, or to meet with her when you are visiting Ward K2.
- ◆ She will give you the same two questionnaires as \_\_\_\_\_ completed, to see how you think they are feeling and coping.
- ◆ We will offer the same questionnaires again when they are about to be discharged to see how things have changed.

## Benefits and risks of the study

We hope that this research will help us to improve how we measure whether people are feeling better.

The people taking part on Ward K2 will have the opportunity to have the questionnaires placed in their patient notes if they would like. Staff could then use the information to better understand their progress and address their needs.

We do not foresee any risks involved in the study.

## Participation

You do not have to take part in this study. It is your choice.

- ◆ You can change your mind at any time and stop the questionnaire, or withdraw your comments. Just let one of the research team know. You do not have to give a reason.
- ◆ You do not have to answer any question that you do not want to.
- ◆ Declining to take part in the study or withdrawing from the study will not affect health care on the ward now or in the future.

## Confidentiality

We want you to feel comfortable telling us what you really think.

- ◆ No material which could personally identify you or the people on Ward K2 will be used in any reports on this study.
- ◆ If you did say in the questionnaires that the person felt like harming themselves, we would always let their treatment staff know.
- ◆ A copy of the questionnaires will be stored in a locked cabinet in the researcher's office for 10 years. This is in case we need to go back to the questionnaires to check anything.

## Results

The information from this study will be used to help us to decide what questions we should routinely ask. We will also share the results in written papers and in talks so that it can help staff in other services.

We would be happy to send you a summary of the results when the study finishes mid 2010.

## General

If you have any questions please feel free to contact Kasia on 376 4510. Or you could contact the Research Associate. Her name is Susan Gee. You can call her on 337 8894.

This study has received ethical approval from the Upper South B Regional Ethics Committee.

If you have any queries or concerns regarding your rights as a participant in the study you may wish to contact a Health and Disability advocate. Their telephone number is (03) 377 7501


## Compensation:

In the unlikely event of a physical injury as a result of your participation in this study, you may be covered by ACC under the Injury Prevention, Rehabilitation and Compensation Act. ACC cover is not automatic and your case will need to be assessed by ACC according to the provisions of the 2002 Injury Prevention Rehabilitation and Compensation Act. If your claim is accepted by ACC, you still might not get any compensation. This depends on a number of factors such as whether you are an earner or non-earner. ACC usually provides only partial reimbursement of costs and expenses and there may be no lump sum compensation payable. There is no cover for mental injury unless it is a result of physical injury. If you have ACC cover, generally this will affect your right to sue the investigators.

If you have any questions about ACC, contact your nearest ACC office or the investigator.

## APPENDIX J

### HUMAN ETHICS COMMITTEE APPROVAL

 <b>Health and Disability Ethics Committees</b>	<b>Upper South B Regional Ethics Committee</b> Ministry of Health 4 <sup>th</sup> Floor, 250 Oxford Terrace PO Box 3877 Christchurch Phone (03) 372 3018 Fax (03) 372 1018 Email: <a href="mailto:uppersouth_ethicscommittee@moh.govt.nz">uppersouth_ethicscommittee@moh.govt.nz</a>
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12 May 2009

Dr Matthew Croucher  
Consultant Psychiatrist  
Psychiatry Service for the Elderly  
Princess Margaret Hospital  
PO Box 800  
Christchurch

Attention: Susan Gee

Dear Dr Croucher

**Ethics Reference Number: URB/09/03/009**  
**Getting better: Evaluating outcome measures for depression in older people in mental health services**  
**Investigators: Dr Matthew Croucher, Ms Susan Gee, Ms Katarzyna (Kasia) Madrzejewska**  
**Locality: Princess Margaret Hospital**

The above study has been given ethical approval by the **Upper South B Regional Ethics Committee**.

**Approved Documents**

- Recruitment brochure
- Information sheet for participants on Ward K2
- Consent form for participants on Ward K2
- Information sheet and consent form version 1 for Mabel Howard Clinic
- Assent form for second phase of data collection
- Self report questionnaires:
  - Self-report cover sheet
  - Geriatric Depression Scale 15 item version (GDS15)
  - Clinically Useful Depression Outcome Scale (CUDOS) Form
  - Additional questions at discharge
- Clinician rating scales:
  - Montgomery and Asberg Depression Rating Scale (MADRS) Form
  - Health of the Nation Outcome Scales 65+ (HoNOS 65+)
  - Clinician Global Impression Scale (CGI)
- Information sheet for collateral source
- Consent Form for collateral source

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Administered by the Ministry of Health      Approved by the Health Research Council      <http://www.ethicscommittees.health.govt.nz>

- Collateral source questionnaires:
  - Self-report cover sheet
  - Geriatric Depression Scale 15 item version (GDS15)
  - Clinically Useful Depression Outcome Scale (CUDOS) Form
  - Additional questions at discharge

#### **Accreditation**

The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

#### **Progress Reports**

The study is approved until **1 June 2010**. The Committee will review the approved application annually and notify the Principal Investigator if it withdraws approval. It is the Principal Investigator's responsibility to forward a progress report covering all sites prior to ethical review of the project in **May 2010**. The report form is available at <http://www.ethicscommittees.health.govt.nz>. Please note that failure to provide a progress report may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

#### **Amendments**

It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

**Please quote the above ethics committee reference number in all correspondence.**

**It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.**

The committee would like to take the opportunity to wish you all the best with your research.

Yours sincerely

*Diana J. Whipp*

**Diana Whipp**  
**Upper South B Regional Administrator**

Email: [diana\\_whipp@moh.govt.nz](mailto:diana_whipp@moh.govt.nz)