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# **The Diagnosis, Prevalence and Prognosis of Delirium in an Older Hospital Population**

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the degree of Master of Philosophy

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**Abstract:**

Delirium is a syndrome which is characterised by a change in cognition, attentional difficulties and alterations to the sleep-wake cycle. In most cases it is caused by the onset of a physical illness. Delirium is more commonly found in older people aged 65 years or older, with prevalence in hospital being as high as 42%. Delirium is associated with negative outcomes such as increased length of hospital admissions, institutionalisation and mortality.

There are tools which can identify and measure delirium and its associated symptoms. The Delirium Rating Scale-Revised-98 is claimed to be a valid tool, but its use in older patients in general hospital has not been fully investigated and there is limited research to support its validity in such a population.

A cohort study of older people with mental health problems admitted to general hospital was used to establish whether the DRS-R-98 was able to distinguish delirium from other mental health problems, to examine the association between DRS-R-98 scores, demographic variables and health problems and to study outcomes associated with delirium. 250 patients over 70 years admitted to hospital as an emergency and likely to have a mental health problem on the basis of screening were recruited and 249 completed a battery of questionnaires including the DRS-R-98 at baseline. 180 days later 121 participants completed a follow-up questionnaire. 128 participants were lost to follow-up due to refusal of the outcomes questionnaire, ill-health, withdrawal, mortality or being un-contactable after the baseline questionnaire.

Delirium was common in the study population (43%). The odds of having delirium increased with the presence of dementia (odds ratio=6.7) and functional disability (odds ratio=4.5). It was not significantly associated with mortality or length of stay in hospital. It was associated with recoverable cognitive impairment.

The DRS-R-98 has reasonable content, concurrent and predictive validity but compared with clinician diagnosis the sensitivity and specificity of the DRS-R-98 were modest (about 0.75). The validity of the DRS-R-98 was not as strongly supported as in other research, which reported sensitivity and specificity as high as 0.98 and 0.77 respectively. This could be due to the differences in participant populations, as the participants of this study were all older patients with mental health problems on general hospital wards.

In view of its ability to discriminate groups the DRS-R-98 is sufficiently valid for use in epidemiological research, but its moderate sensitivity and specificity make it unsuitable for use alone in clinical practice on individual patients, especially in populations where co-morbid dementia is prevalent.

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## **1 WHAT IS DELIRIUM?**

There are different definitions of delirium and those which attempt to provide a consensus definition of the psychiatric diagnosis are complex. This chapter explains what delirium is, its associated symptoms as well as the risk factors and precipitants.

### **1.1 DEFINITION OF DELIRIUM:**

Delirium is a syndrome characterised by a sudden onset of fluctuating, generalised disturbance of cognitive function and consciousness. It is a neuropsychiatric response to physical illness or toxicity within the body (National Institute for health and Clinical Excellence – NICE 2010).

**1.1.2 Definition of cognition:** Cognition is the process by which knowledge is gained and used. It includes the ability to use language, to reason and think as well as the process of memory (Banyard and Grayson 2000).

**1.2 ONSET AND COURSE OF DELIRIUM:** According to the DSM IV-TR (American Psychiatric Association - APA 2000), the features of the onset and course of delirium are:

-An onset over a short period of time (from hours to several days).

-Fluctuation of symptom severity (over minutes to hours).

**1.2.1 Core features:** According to the DSM IV-TR (APA 2000) the core features of delirium are:

-Impairment of attention and difficulty in actively processing information.

-A change in cognition, including memory impairment, tangential thought processes and disorientation of time and place.

-Disturbances to the sleep/wake cycle, including day-time drowsiness and night-time wakefulness.

**1.2.2 Associated features:** Associated features include:

-Disturbances to speech and language, including aphasia (difficulty in communicating verbally) and dysnomia (difficulty in retrieving words or names from memory) (World Health Organisation – WHO 1992).

-Perceptual disturbances, including hallucination or illusions (APA 2000).

-Disturbances to psychomotor function, including hyperactivity, hypoactivity or a mixture of the two (WHO 1992).

-Delusions (WHO 1992).

-Emotional changes (NICE 2010) including emotional lability, apathy, depression and anxiety (Gelder et al. 2009).

**1.2.3 Subtypes:** Two possible subtypes of delirium may be present during the syndrome, and manifest themselves in different ways, hypoactive delirium and hyperactive delirium (Meagher et al. 2008). Hypoactive delirium presents itself in the sufferer becoming apathetic, withdrawn or quiet and a decrease of voluntary movement. The sufferer may also become lethargic, drowsy or comatose. (Schofield 2008).

Hyperactive delirium presents itself in the sufferer becoming hyper-vigilant, agitated, restlessness and in extreme cases physically combative (Sagawa et al. 2009).

The subtypes may indicate differing aetiology of the syndrome with different causes of the delirium producing different presentations (Meagher et al. 1998).

Multiple factors may cause an episode of delirium and these should be monitored throughout the duration of the syndrome (Gelder et al. 2009).

**1.3. AETIOLOGY:** Delirium has many causes and the syndrome has been associated with infections, intoxication and medications, but can also be linked to virtually any medical condition (Fong et al. 2009).

### **1.3.1 Precipitants and causes:**

There are several risk factors which may predispose people to delirium and precipitants which may cause the onset. The more risk factors, the less precipitant is needed and vice versa.

Delirium is associated with infection and can be a marker for its severity (George et al 1997). Renal and electrolyte disturbances may affect homeostasis and in due course have a potentially toxic effect on the brain (Korevaar et al. 2005)

There is also an association between delirium and brain injury. Delirium may occur as a result of the brain injury itself or the associated medical problems (Kennedy et al. 2003). Injury caused by stroke, bleed or infarct is a risk factor for delirium which has been found to develop at, or shortly after, the onset and could be a result of the disruption to neurotransmitter systems. (McManus et al 2009).

Oxygen deprivation, particularly post-operative hypoxia, has been associated with delirium (Kazmierski et al. 2000). This is due to a decrease in oxidative metabolism and a decline in neurotransmitters within the brain (such as acetylcholine) thus causing cognitive dysfunction (Parikh and Chung 1995).

Sufferers of advanced cancer have also been noted to be susceptible to delirium, particularly in those suffering from lung cancer (Lawler et al. 2000). This can be due to hypoxia or liver and renal failure, but has been most strongly associated with the use of opioid pain management (Sagawa 2009)

Anticholinergic medications may cause side effects including cognitive dysfunction, which could lead to the development of delirium (Tune 2001). The development of delirium has also been linked to drugs such as benzodiazepines and opiates (Alagiakrishnan and Wiens 2004). Where multiple risk factors are present one dose of a hypnotic may be enough to contribute to an onset of delirium thus acting as a precipitant (Inouye 2006). In addition, the low level anticholinergic effects of many drugs are cumulative and polypharmacy is implicated.

The withdrawal from long-term alcohol and opiate use may cause 'alcohol induced psychosis' or delirium tremens (DT) (Eyer et al. 2001). The symptoms of delirium tremens, such as hallucinations and memory impairments, manifest themselves in a similar way to delirium and a marked tremor can occur (Gelder et al. 2009).

Sleep deprivation has been associated with changes in mental status (Weinhouse et al. 2009) and may cause delirium. During sleep the brain repairs defective processes and allows the brain to return to a state where it can process new knowledge. Therefore if sleep deprivation occurs it may become a risk factor for developing delirium (Sanders and Maze 2010).

### **1.3.2. Predisposition and risk factors:**

**1.3.2.1 Age:** Delirium is more commonly found in older people during an acute illness (Korevaar 2005), with the prevalence in hospitalised older people ranging from between 14% and 24% on admission units (Inouye 1998), from 15% to 53% after an operation (Agostini and Inouye 2003) and 70% to 87% in intensive care (Pisani et al. 2003). Incidence of a new delirium during hospital admission ranges from 3% to 29% (Siddiqi et al. 2006). There are a number of theories as to why this group appears to be more vulnerable to the syndrome.

Older people are more likely to suffer from a greater number of physical illnesses which may be risk factors and increase the likelihood of developing delirium (Lindesay 2009). As delirium is a syndrome with more than one cause, an older person already suffering from a number of illnesses could have a greater number of precipitants than a younger person (Young and Inouye 2007). Older people may be more likely to suffer from cardiac or respiratory illnesses which, may lead to an onset due to a reduction of oxygen in the brain (Gelder 2009).

Within this age group there is a rise in the prevalence of a pre-existing cognitive impairment, the presence of which increases the likelihood of developing delirium if the sufferer becomes physically unwell (Iseli et al. 2007).

**1.3.2.2 Dementia:** Dementia is a chronic global cognitive impairment with an insidious onset (The Royal College of Psychiatrists, 2005) which can be seen as a key risk factor for developing delirium (DSM-IV-TR). As both delirium and dementia cause cognitive problems, delirium may be mistaken for dementia (Trzepacz et al. 1998). The fundamental differentiating factors are that, unlike dementia, delirium has a sudden onset and symptoms fluctuate in their severity (APA 2000). Delirium may be superimposed on dementia, causing a worsening in cognitive function from the pre-existing level (Fick et al. 2007). Delirium can be more difficult to identify in people suffering from end-stage dementia and Lewy Body dementia, both of which can result in a chronic delirium-like state (Trzepacz et al. 1998).

**1.4 NEGATIVE OUTCOMES:** Delirium is associated with a number of potential negative outcomes.

Delirium is associated with an increase in the death rate in sufferers, both during and shortly after discharge from hospital, with an increase of 25% to 33% within six months (Inouye 2000).

Delirium may worsen dementia: The syndrome itself may be a predictor of future episodes of delirium and it may also be a significant marker of further cognitive and functional decline (Adamis et al. 2006). Delirium may be a marker of subsequent dementia in older people, with incidence of dementia rising from 5.6% to 18.1% in the three year period after the initial onset of delirium (Rockwood et al. 1999). Although the symptoms of delirium may be reversible, cognitive recovery may not be assured and the delirium may persist. It has also been reported that 6 months after the onset is detected, persistent delirium is still prevalent in 21% of cases, (Cole et al. 2009) and twelve months after the onset, both functional and cognitive ability may be worsened (Young and Inouye 2007).

There has also been shown to be an increase in institutionalisation for sufferers of delirium after discharge from hospital, the arrangements for which may also increase the length of stay in hospital (George et al. 1997).



However the degree to which delirium or the conditions with which it is associated are causally associated with negative outcomes is unclear.

**1.5 RESOURCE USE:** Delirium has been associated with an increased length of stay in hospital and a greater need for medical services (Saravay 2004). This could be due to the length of time needed to treat both the physical illness and the delirium, or because of the behavioural problems associated with delirium, such as non-compliance with treatment (Milisen et al. 2004).

**1.6 AWARENESS:** Although commonly present in hospitals, delirium is often not detected by healthcare professionals (Anderson 2005). Identifying the syndrome is not always straightforward due to the fluctuation and heterogeneity of the symptoms (Siddiqi 2006).

In order to screen for possible delirium during hospital admission, risk factors (as mentioned) should be taken into account, changes to behaviour and cognitive ability recorded and possible symptoms of delirium noted (NICE 2010). Quantitative delirium screening and rating tools have been designed for and implemented in diagnosis. These may be used during a patient's admission to identify an onset of delirium, and can be used to monitor the effectiveness of medication during treatment (Trzepacz et al. 2001).

However, even in high-risk wards such as orthopaedics (on which the likelihood of delirium is increased) screening is rarely carried out (Holmes and House 2000).

A history should be taken from any reliable informant (such as a relative or carer) in a cognitively impaired patient (Bruera et al. 2009). The lack of cognitive history may explain why dementia and delirium are under diagnosed, as "confused" patients may simply be left without a diagnosis. If available, it can allow a clinician to ascertain a baseline of cognitive function prior to the onset of the delirium, to identify the effect the delirium has had. In cases where a person with delirium has a pre-existing dementia,

an informant can identify the suddenness of any onset of increased cognitive impairment (APA 2000).

**1.7 REDUCE IMPACT:** Delirium can be treated and may resolve within days or weeks (Cole 2009). Healthcare systems and the management of patients may increase the likelihood of developing delirium (Young and Inouye 2007). The management of those at risk of developing delirium and treatment if the syndrome occurs may reduce negative outcomes associated with delirium.

The use of many drugs, especially those which may cause sedation or anticholinergic effects have been associated with delirium (Attard 2008). On admission a review of current medications and a reduction in unnecessary drugs may be advised (NICE 2010).

While not a causal factor, environmental strategies (such as clear signposting around the ward and the use of clocks) and the provision of orientation aids may be used to reduce the manifestations of the illness, such as agitation (Burns et al. 2004). As sleep deprivation has also been linked to the development of delirium noise reduction and ensuring a dark environment at night time may also help to prevent onset (Weinhouse 2009).

Patients with delirium may become more agitated in hospital if they suffer from sensory impairments such as visual or hearing difficulties (Anderson 2005). These may exacerbate the confusion they experience and increase the likelihood of developing delirium. Despite the lack of thorough research, it appears that simple interventions such as the provision of a patient's hearing aid and glasses may reduce the severity and duration of the episode of delirium (Mahony et al. 2011).

The presence of family and friends may help to re-orientate those suffering from delirium (Meagher et al. 1996). They may be able to provide the sufferer with reassurance (Anderson 2004) as well identify any change in the sufferer's cognitive status (Bruera et al. 2009).

Addressing constipation and dehydration may help to reduce the impact of delirium (Mahony et al. 2011). The avoidance of falls, pressure sores and over-sedation in the sufferer may also reduce the impact and aid the resolution of the symptoms (Ross and Alexander 2001).

**1.8 TREATMENT:** Prompt treatment of the underlying illness or infection is critical in managing delirium (APA 2000). Symptoms of delirium may also be treated using antipsychotics such as haloperidol (Attard et al. 2008). Improvement in cognitive ability may occur within 24 hours after a low dose (Ross and Alexander 2001). However, such treatment has been associated with over-sedation and side effects such as hypotension and premature death in those suffering from dementia (Seitz et al. 2007).

It must be noted that, in order to treat delirium it must first be identified. Diagnostic criteria and screening tools are available to aid in this task and allow accurate diagnoses to be carried out.

From this overview it can be seen what delirium is, its associated symptoms, the risk factors and precipitants which may lead to an onset and the impact it can have on sufferers and resources. An aim of this thesis was to identify a valid tool to diagnose delirium and distinguishing it from other mental health problems. The first stage was to look at different tools available and how they identify delirium. From this the validity of the most appropriate tool could be analysed and by using it to detect delirium in a cohort of older people with mental health problems identify the factors and outcomes associated with having delirium.

## **2 DIAGNOSING AND RATING DELIRIUM:**

**2.1 INTRODUCTION:** Delirium is associated with negative outcome and the phenomena may be distressing to family and other carers, meaning that the syndrome requires explanation and treatment. One of the key issues surrounding this issue appears to be early recognition of the syndrome (NICE 2010). Delirium is common in older patients on general hospital wards, but it is not always detected by healthcare professionals meaning that the prevalence may be under-estimated and in some cases treatment may not be given. Alternatively symptoms may be misinterpreted as a permanent cognitive impairment (Schofield 2008) leading to inappropriate decision making in terms of treatment. The use of delirium diagnostic tools on general hospital wards could increase identification of the syndrome which could potentially lead to treatment and a decrease in the associated negative outcomes (Lindesay 2009).

Whilst there are a great many tools available, only those which may be used specifically in the diagnosis and rating of delirium and for which there is an established evidence base have been examined.

### **2.2 DIAGNOSTIC CRITERIA:**

Both the ICD-10 and DSM-IV-TR provide diagnostic criteria from which delirium can be identified. However, while the ICD-10 provides a coding system for all diseases the DSM-IV-TR was designed to be used by psychiatrists and is specific to the diagnosis of mental disorders (Andrews et al. 1999). Both definitions are given in this chapter as both may be used by health care professionals.

**2.2.1 International Classification of Disease (ICD-10):** Designed to be used by medical doctors and psychiatrists, the ICD-10 provides diagnostic criteria for clinical and research use (WHO 1992).

The ICD-10 states that for a diagnosis of delirium to be made there should be symptoms presenting of each of six core areas: clouding of consciousness; change in cognitive abilities (including memory problems and disorientation); psycho-motor

problems; disturbance to sleep/wake cycle; underlying physical illness and acute onset with fluctuations in symptom severity (see figure 1). The ICD-10 also highlights the need to gain a history of the patient's pre-syndrome cognitive ability before a formal diagnosis and provides criteria for not only delirium but also delirium complicating dementia (WHO 1992).

It has been argued that the criteria are restrictive and the tool's sensitivity poor (Lindesay 2009). This could lead to fewer diagnoses of delirium being made due to the incorrect identification of sufferers of delirium as not having the syndrome.

**2.2.2 Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR):** The most recent revision of this diagnostic manual lists inclusion/exclusion criteria for delirium based on clinical findings associated with the syndrome (APA 2000) (see figure 1). The DSM-IV-TR also emphasises the importance of gaining an accurate history of the patient's prior cognitive ability so that a misdiagnosis of dementia may not be made. In addition the guidelines stress language difficulties (such as aphasia) that a sufferer of delirium may experience, which may present when the DSM-IV-TR user interviews the patient (APA 2000). It is often considered to be the gold-standard when identifying delirium (Radtke 2008).

The DSM-IV-TR provides guidelines to diagnosing delirium but is written by and for qualified doctors who have received training in the diagnosis of a number of cognitive impairments and mental health problems (DeJonge et al. 2005).

### **2.3 MEASURING COGNITIVE CHANGES AND IMPAIRMENT: Mini Mental State**

**Examination:** (Folstein et al. 1975): This tool was primarily designed to be a screening tool for cognitive impairment but can be used to indicate a change in cognitive function, and identify the onset of an impairment associated with delirium. Whilst not diagnostic in its own right, it can be used to alert clinicians to the presence of cognitive dysfunction (Lindesay 2009) by drawing attention to symptoms associated with delirium such as disorientation, attentional disturbances, language difficulties and memory problems. It allows a 'snap shot' of the patient's cognitive function and can identify

changes during an episode of delirium (Breitbart et al. 1997). Its questions, either in its entirety, or the few directly related to orientation, attention and memory have been taken and used to form conclusions about deficits to these abilities in other tools.

**2.4 SCALES:** The criteria reported in the ICD-10 and DSM-IV-TR provide a diagnostic framework for healthcare professionals and the basic structure of other, more easy to use screening and rating tools.

**2.5 SCREENING SCALES:** Tools which are designed to identify persons who do have an illness or syndrome from those who do not (Wilson and Jungner 1968).

**2.5.1 Confusion Assessment Method (CAM):** This tool was created to aid the diagnosis of delirium. It involves the measurement of the fluctuation and severity of 9 features of delirium: acute onset; inattention; disorganised thinking; altered level of consciousness; disorientation (to time, place and person); memory impairment; perceptual disturbances; psychomotor agitation or retardation; and altered sleep-wake cycle (Inouye et al. 2003). An algorithm based on the core features of delirium as reported by the DSM-III is then used, and, if potential sufferers are found to have an acute onset with a fluctuating course, inattention and either altered level of consciousness or disorganised thinking then a diagnosis of delirium is suggested (Inouye et al. 2000).

CAM has good sensitivity (values between 77% and 100%) (Hestermann et al. 2009) (Vreeswijk et al. 2009) and specificity (between 84% and 99%) (Laurila et al. 2002) (Gonzalez et al. 2004). It also has high positive predictive values (between 94% and 100%) and negative predictive values (of between 97% and 100%) when used in an emergency department setting (Monette et al. 2001). This indicates that CAM is a valid tool which can be used to detect the presence or absence of delirium. CAM has also been shown to be an accurate tool when used in intensive care units (Meagher 2001). However, when nurses use CAM the levels of sensitivity and specificity are affected, and decrease to 67% and 91% respectively (Lemiengre 2006). This suggests that prior

training and the ability to identify the underlying features of delirium are needed in order to use this tool to identify the presence of the syndrome (Reade et al. 2011).

**2.5.2 CAM-ICU:** This tool differs from CAM in that it measure symptoms of delirium in severely unwell patients using the following two steps: the first being to rate the level of consciousness from a score of +4, representing severe motor agitation to the extent where the patient becomes combative, to -5 where the patient is unrousable (Ely et al. 2001<sup>a</sup>). Step two involves noting the presence of 4 delirium features: presence of an acute change or fluctuation of symptoms; presence of attentional difficulties; a change in the level of the patient's consciousness; and the patient demonstrating disorganised thinking. CAM has been found to have a sensitivity of 95 -100% and specificity of 89 – 93% (Ely et al. 2001<sup>b</sup>).

It is also important to note diurnal variations, differences in sleep-wake cycles and emotional disturbance are not measured by CAM-ICU and that factors such as sedation and intubation (which are common on an ICU) may complicate the diagnosis when using this tool (Hewson-Conroy et al. 2011).

**2.5.3 NEECHAM Confusion Scale:** The NEECHAM Confusion Scale (NEECHAM) is a nursing screening tool which was designed to detect delirium quickly in acutely unwell hospital patients, but has also been used in intensive care units (Vreeswijk et al. 2009). It measures and rates the symptoms and physical indicators for delirium. It measures symptoms at three levels: level 1 measures information processing (attention, following commands and orientation). Level 2 measures behavioural symptoms (the person's appearance, motor function and language difficulties). Level 3 consists of physiological measures (abnormal temperature, systolic blood pressure, diastolic blood pressure, heart rate, respiration rate and oxygen saturation) (Neelon et al. 1996).

The NEECHAM scale has a sensitivity of between 86 and 95% and specificity of 78 -87% in patients on both medical and surgical wards (Neelon et al. 1996) (Van Gemert and Schuurmans 2007).

**2.5.4 Delirium Observation Screening scale (DOS):** The DOS is a 25 item scale designed to aid nursing staff in the recognition of delirium whilst delivering care (Schuurmans et al. 2001). After clinical studies the 25 items were reduced to 13: orientation (to time and place); consciousness; ability to maintain attention (both in actions, speech and distractibility); language; memory; motor behaviour (hyper and hypo activity); hallucinations; emotional lability (Scheffer et al. 2011). When used by nursing staff the DOS has been found to have a sensitivity of 89% and 94% and specificity of 76% and 88% (Van Gemert and Schuurmans 2007)(Schuurmans et al. 2003).

**2.5.5 Cognitive Test for Delirium (CTD):** The CTD is a screening tool designed to identify delirium in an intensive care settings in patients who cannot speak (Trzepacz et al. 2001). Non-verbal methods of communication are used to test for the items of: concentration; consciousness; memory; orientation; understanding and reasoning. (Hart et al. 1996).The CTD has been found to have sensitivity of 72% and 100% and specificity of 71% and 99% (Hart et al. 1996) (Kennedy et al. 2003).

**2.5.6 Nursing Delirium Screening Scale (NuDESC):** The NuDESC is a 5 item screening scale designed to be used by nursing staff throughout a working shift and rates the presence of ten symptoms: hallucinations (both auditory and visual); language difficulties; behavioural problems; motor retardation; and disorientation (Gaudreau 2005). It has been reported as having a sensitivity of 85% - 95% and specificity of 86% -87% (Gaudreau 2005) (Radtke 2008).

**2.6 SEVERITY SCALES:** These are tools which have two uses. With a cut-off point they distinguish the presence or absence of an illness while at the same time quantitatively measuring the severity of the symptoms present.

**2.6.1 Delirium Index (DI):** The DI was designed to rate the presence and the severity of delirium symptoms in elderly patients, and scores are based solely on the



researcher's or clinician's observation of the patient (Schuurmans et al. 2003). The index is designed to be used alongside the MMSE, using at least the first five questions as the basis of observed symptoms. It also measures seven of the ten symptoms assessed by CAM: disorganised thinking; inattention; altered state of consciousness; memory impairment; disorientation; perceptual disturbances; psychomotor agitation and psychomotor retardation (McCusker et al. 2004). Unlike the CAM, the DI allocates scores from 0 (meaning the symptom is not present) to 3 (meaning the symptom is present and at its severest) and provides an overall score to 'rate' the delirium.

When used alongside the Informant Questionnaire of Cognitive Decline in the Elderly (IQCODE) it distinguishes between symptoms caused by delirium and those caused by dementia. This may increase the specificity of the tool and also allows the identification of delirium superimposed on dementia, as levels of pre-existing cognitive impairment will be known and a sudden onset of worsening dysfunction can be identified (Jorm 2004).

However, due to the differences in scoring between CAM and the CAM questions posed by the DI (in that a rating system is in place), the resulting conclusions made by the DI may exaggerate the number of symptoms and lower the specificity of the scale (Cole et al. 2002).

**2.6.2 Memorial Delirium Assessment Scale (MDAS):** The MDAS was designed to provide clinicians with an aid to diagnose and rate the symptoms of delirium and to measure the changes in those presented during medical intervention (Lawlor et al. 2000). The MDAS is based on the DSM IV's criteria for delirium as well as symptoms noted previously in the DSM IIIR. The MDAS is a ten item scale measuring: reduced consciousness; disorientation; short-term memory impairment; ability to repeat digits; disorganized thinking; reduced ability to maintain and shift attention; hallucinations or illusions (information also provided by informants); delusions; abnormal motor behaviours and altered sleep-wake cycle.

Analysis of this tool has revealed that it has high levels of specificity (between 75 and 100% though only modest levels of sensitivity (between 65 and 96%) (Breitbart et al. 1997) (Lawlor et al. 2000).

**2.6.3 Delirium-O-Meter (DOM):** The DOM is a 12 item tool designed for nursing staff to quickly rate behaviours associated with delirium (Vreeswijk et al. 2009). Based on the DSM-IV, the content of the scale is similar to the DOS, NEECHAM, DRS and CAM and rates the symptoms of delusion, hallucinations, difficulty sustaining or shifting attention, hypoactivity, hyperactivity, fluctuation of functional ability, consciousness, language difficulties, disorientation as well as anxiety and apathy levels (de Jonghe et al. 2005). Although little evidence is available, DOM has a reported specificity of between 66.7% and 83% and is sensitive to change (de Jonghe et al. 2005).

**2.6.4 Delirium Rating Scale (DRS):** Based on the DSM III, the DRS is a 10 item scale designed for clinicians to detect and rate symptoms of severity after patient interview (Trzepacz et al. 1988). These items are: hallucinations; delusions; cognitive status; psychomotor behaviours; lability of mood; fluctuation of symptom severity; disturbance to the sleep/wake cycle and presence of an underlying physical disorder (Trzepacz et al. 1988). The reported sensitivity of the scale is between 94% and 98% and specificity between 62% and 94% (Trzepacz 1999) (Rosen et al. 1994) (Grassi et al. 2001). It is designed to evaluate the prevalence and severity of delirious symptoms by measuring criteria for temporal onset and variability compared to the patients' usual presentation. It does this by investigating not only the presentation available to the clinician or researcher at the time of the interview but also by ascertaining data from the patient's history (Bosisio et al. 2006). The DRS is able to distinguish between delirium and other disorders by asking questions specific to the syndrome, such as those around physical illness (Trzepacz 2001); however, it has been shown to have limited validity in differentiating between delirium and other organic mental illnesses (Trzepacz 1999). Despite this, the sensitivity of the DRs-R-98 allows clinicians to

measure the effectiveness of treatments based on changes in symptom severity (Meagher et al. 2008).

**2.6.5 Delirium Rating Scale – Revised – 98:** In 1998 a revised version of the DRS was produced by the original author. As well as the items included in the DRS, the DRS-R-98 also includes items which allow the scale to be repeated throughout the patient's hospital admission so it can be used to detect the onset of delirium and measure its progression throughout treatment (Trzepacz et al. 2000). As in the original version, it measures the onset and fluctuation of symptoms and uses information from interviews with both the patient and an informant. The revised version is a 16 item scale split into two sections; 3 diagnostic items to be recorded on initial rating and 13 items which may be repeated to measure effectiveness of treatment (Wong et al. 2010). In the revised version of the DRS the item measuring cognitive difficulties is split into five separate factors of; orientation, language, visuospatial ability and short and long term memory problems (see appendix 1). The original DRS item measuring psychomotor behaviour is split into two thus measuring and distinguishing between motor retardation and motor agitation (Trzepacz et al. 2001).

**2.7 REVIEW:** Using the diagnostic features identified in the two diagnostic manuals, the ICD-10 and DSM-IV-TR, Figure 1 details the comparison of the items measured in each tool.

**Figure 1: Items measured by screening and rating scales of delirium**

Symptoms	ICD - 10	DSM-IV-TR	CAM	CAM -ICU	NEECHAM	DOS	CTD	NuDESC	DI	MDAS	Delirium-O-Meter	DRS	DRS-R-98
Change in cognition	X	X <sup>1</sup>	X	X <sup>2</sup>		X	X <sup>5</sup>		X	X		X	X
Symptom fluctuation	X	X	X	X				<sup>6</sup>			X	X	X
Sudden onset	X	X	X	X								X	X
Physical illness	X	X			X							X	X
Impairment of attention	X	X	X	X	X	X			X	X	X		X
Consciousness	X	X	X	X		X	X		X	X	X		X
Disorientation	X	X	X		X	X	X	X	X	X	X		X
Memory impairment	X	X	X			X	X		X	X <sup>7</sup>			X
Disturbance to sleep/wake cycle	X	X	X	X					X	X		X	X
Disturbance to psychomotor function	X	X	X	X	X	X		X	X	X	X	X	X
Distinguishes hypo from hyperactivity	X		X	X		X		X	X		X		X
Language disturbances		X			X	X		X			X		X
Mood/Emotions	X	X				X					X	X	X
Delusions		X								X	X	X	X
Hallucinations	X	X	X			X		X	X	X	X	X	X
Other					X <sup>3,4</sup>								

<sup>1</sup> includes changes to visuo-spatial ability.

<sup>2</sup> described as 'disorganised thinking

<sup>3</sup> person's appearance

<sup>4</sup> physiological measures of temperature, blood pressure, heart rate, respiration rate and oxygen saturation

<sup>5</sup> includes understanding and reasoning

<sup>6</sup> whilst there is no specific item to measure the fluctuation of symptom severity, measures are taken over three 12- hour periods which may highlight this

<sup>7</sup> pecifies short-term memory impairment and ability to repeat digits

The DRS-R-98 was chosen as the measure of delirium in this research. The reasons for this choice were: Evidence indicates that it is compatible with other scales and easy to use (Adamis et al. 2010). While there is research supporting the validity of the CAM in diagnosing delirium (Ely et al. 2001<sup>a</sup>) it requires that the user must have specialist training and be able to identify the underlying features of delirium before adequate levels of sensitivity and specificity of diagnosis are achieved (Lemiengre 2006). DRS-R-98 does not appear to lose sensitivity when used by someone other than a psychiatrist, meaning that it could be utilised by a more multi-disciplinary staff (Trzepacz 1999).

As the DRS-R-98 was to be used in general hospital wards the use of the CAM-ICU or CTD, both of which were designed to be used in ICU settings, was not considered. The NEECHAM, NuDESC, DOM DOS and DI reported modest levels of specificity, meaning that there is a possibility that the prevalence of delirium may be exaggerated.

The DRS-R-98 also appears to have an acceptable scope of symptom coverage, being composed of items which include all the symptoms noted by both the DSM-IV-TR and ICD-10 (Trzepacz et al. 2001) and has a degree of flexibility with ratings being based on examination, patient interview, patient's history and reports from nursing staff and family (Fonseca et al. 2005).

However, there may be problems with the ability of the DRS-R-98 to distinguish delirium from other mental health problems, most notably dementia. Though the scale's author reports that the DRS-R-98 is able to distinguish delirium from dementia, schizophrenia and depression (Trzepacz et al. 2001), there is evidence that the sensitivity and specificity are compromised when used to identify the presence of delirium in participants suffering from dementia (Andrew et al. 2009).

Therefore, before analysing the results and associations of DRS-R-98 scores within the cohort study, the validity of the tool was first examined. In order to do this the different aspects of validity were first defined.

### **3 VALIDITY AND HOW IT IS MEASURED**

**3.1 DEFINITION:** Validity refers to the extent to which a test or measure actually measures what it is intended to (Banyard and Grayson 2000). It is only when a test is seen to be valid that inferences can be made about the data it is designed to collect, for example the characteristics of a person or group that the test was designed to measure (Bowling 2009).

There are different aspects of validity which may be examined, however the three key types are content validity, criterion validity and construct validity.

**3.2 CONTENT VALIDITY:** The content validity of a test refers to the extent to which its content is representative of the desired concept and the particular body of knowledge from which the test derives. This means that even if broader questions regarding the same topic were added to the scale, the new scale and the original scale should still allow the user to come to the same conclusions (Walsh and Betz 2000). Therefore if a scale has good content validity accurate inferences can be made, as it reflects the all aspects of the overall topic. It describes whether any important items are missing.

Content validity is not tested through the analysis of the test's scores, but from critical reviews or empirical qualitative data from those who know about the field and can make judgements on whether the test appears to cover key aspects of the field (Bowling 2009) (in this case, whether the DRS-R-98 includes the measurements of key symptoms commonly associated with delirium). Due to this, content validation may be subjective to those who are critiquing it. However, as content validity can be demonstrated with thorough research into the field, thoughtful planning and with pre-testing, it could be argued that such a process can show how representative a scale is to the concept it purports to measure and as well as being important during scale development.

**3.2.1 Face validity:** This is related to, and overlaps with, content validity. Face validity can also be used to assess how the test is relevant when measuring a trait or symptoms, and whether it contains the items that one would expect (Steiner and Norman 2008). This measure of validity is not robust, as it is based on the assessments of the investigators themselves and may be subject to bias; however it can allow potential users to assess the usability of the scale.

**3.3 CRITERION VALIDITY:** This is the extent to which the scale is associated with, or relates to, another test, which measures the same phenomenon (for example the same set of symptoms). The test against which the scale is measured is ideally one that is independent of the scale and is accepted as a 'gold standard' in the field (McDowell and Newell 1996). The 'gold standard' is called the criterion and should be seen as a true indicator of the topic (in this case, diagnosis).

Criterion validity is usually split up into two distinct types:

**3.3.1 Concurrent validity:** Concurrent validity is established when the scale and the criterion are conducted at the same time, and the different scores are assessed to see how much they correlate (Bowling 2009).

**3.3.2 Predictive validity:** Predictive validity is established when the scale is used to predict future outcomes. These are often categorical, for example whether participants died or survived and are measured some time after the scale (measuring the original trait) is used.

For both measures of criterion validity, if both the scale and the criterion are continuous, the Pearson correlation coefficient may be used to clearly demonstrate a strong association between the 'gold standard' criterion and the tested scale. If this is the case then the concurrent and predictive validity may be supported and the new scale may be said to be measuring similar traits (or symptoms) to that of the 'gold standard' (Bowling 2009).

**3.4 CONSTRUCT VALIDITY:** This is used to measure attributes for which there is no one specific measure and no one criterion on which to assess validity. Construct validity can be used to show whether a theory (or construct) is being supported and that the test being used reflects this (Banyard and Grayson 2000).

In order to analyse this, the theory must be clearly defined. Construct validity can help to show whether the scale behaves in a way that one might expect. This can be supported by testing the internal consistency of the scale, using Cronbach's alpha or factor analysis. Construct validity may also be assessed by measuring the convergent and discriminate validity.

**3.4.1 Convergent validity:** This may be assessed by analysing how closely the tested scale correlates to measures of other things that are likely to be related to the scale. While the correlation between the tested and similar scales should be higher, in order to demonstrate construct validity, they should not be too high (as this indicates that they measure the same thing) (Walsh and Betz 2000).

**3.4.2 Discriminant validity:** This may be assessed by analysing whether the scale does not correlate with scales or variables of a different construct. A strong correlation between two scales reporting to measure different, independent topics should not be found. If it is, this could mean that the scale is measuring something unexpected, or that the test items should be reviewed (McDowell and Newell 1996).

**3.5 ASSESSMENT OF VALIDITY - Test performance:** Sensitivity and specificity may also be used to test validity of a scale or test. These are often used to test the validity of diagnostic tools against a 'gold standard' (Bowling 2009).

**3.5.1 Sensitivity:** This refers to the ability of a test to detect when a condition (for example delirium) is present. Calculated as a percentage, it helps to identify the number of participants with the condition for whom the scale reports they do not (the false negative or 1-sensitivity) (Bowling 2009).



**3.5.2 Positive Predictive Values:** In testing for specificity a positive predictive value may be calculated to measure how many of the participants scoring positivity on a test for a condition were correctly diagnosed (Kirkwood and Sterne 2003).

**3.5.3 Specificity:** Specificity refers to the ability of a test to detect when a condition is not present.

**3.5.4 Negative Predictive Values:** In testing for specificity, negative predictive values can be used to indicate how many participants with a negative test result are correctly diagnosed as not having the condition (McDowell and Newell 1996).

**3.5.5 Sensitivity to change:** Also known as responsiveness, sensitivity to change refers to the ability of a scale to detect any changes which may occur over time in an individual or sample (Bowling 2009).

**3.5.6 Receiver Operating Characteristic (ROC) curves:** ROC curves may be used to investigate the ability of a test to discriminate who does from who does not have a condition. A ROC curve can be used to represent graphically all the potential cut-off scores for a continuous scale by plotting the true-positive probability (sensitivity) against the false-positive probability (1-specificity). The scale performance can be qualified using the area under the curve (Steiner and Norman 2008).

**3.6 LIKELIHOOD RATIOS:** Likelihood ratios may also be used to allow us to see the comparisons of the probability of a participant screening positively for a condition (and actually having) against the probability of someone who does not have the condition (McDowell and Newell 1996). It is a measure of the information value added by a test result.

There are two equations for the likelihood ratio. The likelihood of a positive test result (LR+) is calculated as such:

$$LR+ = \frac{\text{sensitivity}}{1-\text{specificity}}$$

The likelihood of a negative test result (LR-) is calculated as:

$$LR - = \frac{1 - \text{sensitivity}}{\text{specificity}}$$

**3.7 RELIABILITY:** Reliability (or repeatability) refers to how consistent a test is when measures are taken. This means that if different raters use the scale at different times under different circumstances the results will remain consistent and may be replicated (Porter 2008).

**3.7.1 Test-retest reliability:** Test-retest reliability can be used to investigate the repeatability of a scale. This is conducted by looking at the agreement of scores from repeated administrations by different raters on the same sample over a period of time where the underlying condition has not changed. Kappa values may be calculated for categorical scales, where a value of 1 indicates true agreement and 0 indicates that any agreement has come about only by chance. Intraclass correlation coefficients (ICC) may be calculated for continuous scales (Bowling 2009).

**3.7.2 Inter-rater reliability:** This refers to agreement of scores when a scale is used by different raters on the same sample. As above, Kappa value or ICC may be calculated to review the proportion of agreements between different raters' scores (McDowell and Newell 1996).

Whilst scale validity is an important way to assess the accuracy and consistency of a scale, it must be noted that scales can only be said to be validated in specific contexts, these being the environment and population (including their diagnoses) in which the validation study took place. A scale may not be seen to be truly 'validated', so a potential user must first judge whether the scale is adequate for their purpose, for example detecting delirium in inpatients on a general hospital ward.

Having defined validity and how it can be measured, the evidence that supports the validity of the DRS-R-98 can be examined and used to determine whether the DRS-R-98 is a valid tool which can be used to identify delirium and distinguish it from other mental health problems.

## **4 VALIDITY OF THE DRS-R-98 AND WHAT IT MEASURES: A Systematic Review**

**4.1 AIMS:** To critically examine the evidence of the validity of the DRS-R-98.

To determine if the DRS-R-98 can distinguish people with and without delirium, including those suffering from other psychiatric disorders including dementia, on general hospital wards.

### **4.2 METHOD:**

A systematic approach was taken to review the available literature.

The journals included were all from 1998 onwards as this was the date that the DRS-R-98 was introduced.

**4.2.1 Databases:** The following databases were searched (timeframe from 1998 to present);

- Ovid Medline (1996+)
- Embase (1980+)
- Psych Info (1806+)
- Web of Science (1955+)

**4.2.2 Search terms:** The following search terms were used;

1. 'Delirium Rating Scale' or 'DRS-R-98' in order to identify the scale.
2. 'Delirium' or 'Dementia' or 'Psychotic' or 'Psychosis' to identify the mental illness.
3. 'Aged' or 'Aged 80 and over' or 'Elder\$' or 'Older persons' to identify the population.
4. 'Inpatient\$' or 'Acute disease' or 'Acute illness' or 'Hospital\$' to identify the setting.
5. 'Sensitivity' or 'Validity' or 'Specificity' or 'Efficacy' or 'Reliability' to identify measurements of quality and validity by which the DRS-R-98 can be assessed.

The search terms were adapted for each database in order to conform with the searching strategy required for each system.

**4.2.3 Inclusion criteria:** Studies were selected if they met the following search criteria;

- Published studies.
- Primary research
- Included participants aged 65 or above.
- Used the DRS-R-98 in all cases.
- Included participants with and without other mental illnesses or cognitive impairments.
- Included participants recruited from general hospital settings.
- Used a 'Gold Standard' to determine whether the DRS-R-98 is measuring delirium and is able to distinguish between that and other mental health illnesses (including Dementia).
- Specificity and sensitivity to be cited or calculable.

**4.2.4 Exclusion Criteria:** Studies were not selected if they met the following exclusion criteria;

- Participants exclusively younger than 65 years of age.
- Studies drawing exclusively from non-general hospital settings.
- Studies involving predominantly alcohol, brain injury and/or cancer related delirium.
- Non-English language publications.
- Studies in which the DRS-R-98 was not utilised.
- Reviews.
- Participants not recruited from general hospital wards.

Duplicates of papers were then removed, inclusion and exclusion criteria applied to the remainder and relevant studies identified. In addition references of selected

papers were searched and papers known to the author considered, in order to ensure that key papers were not missed.

**4.2.5 Data extracted:** For each study identified and read the following were recorded;

- The study setting.
- The sample population including age and mental illness, including which mental illnesses (if any) the comparison groups suffered from.
- Population size.
- Methods used to collect data, for example; whether researchers executed the assessments simultaneously, whether a 'Gold Standard' diagnosis was made, whether researchers were blinded, etc.
- What comparative tools were used.
- Overall findings.
- The types of validity of the DRS-R-98 that the study supported, including levels of sensitivity and specificity noted in the study.
- Methodological issues of each study were also noted in order to recognise potential bias or confounding variables (such as other mental illnesses) which could have influenced results.
- Identification of any gaps or weaknesses in the existing literature which may provide a focus for further study.

For the papers that met the inclusion criteria and were not discarded due to the exclusion criteria, a proforma was created and used to extract data from each of the papers selected by the systematic literature search. This ensured that data extraction was standardised, methodical and easy to conduct.

### **4.3 RESULTS:**

In the search stage 56 references or citations, all of which had abstracts were identified, one of which found through hand searching references of articles identified from the

electronic search. Twenty five were duplicates and four were excluded as they were published prior to 1998. A further two studies were excluded because they did not use the DRS-R-98 but other delirium measurement scales instead and four studies were excluded as they utilised the older version of the DRS rather in its revised form.

#### 4.3.1 Selection of papers:

Web Of science search terms:

DRS-R-98 OR Delirium Rating Scale – R – 98

AND

Delirium OR Dementia OR Psychotic OR psychiatric disorders

AND

Aged OR 'Aged, 80 and over' OR Elder\$ OR Older person\$

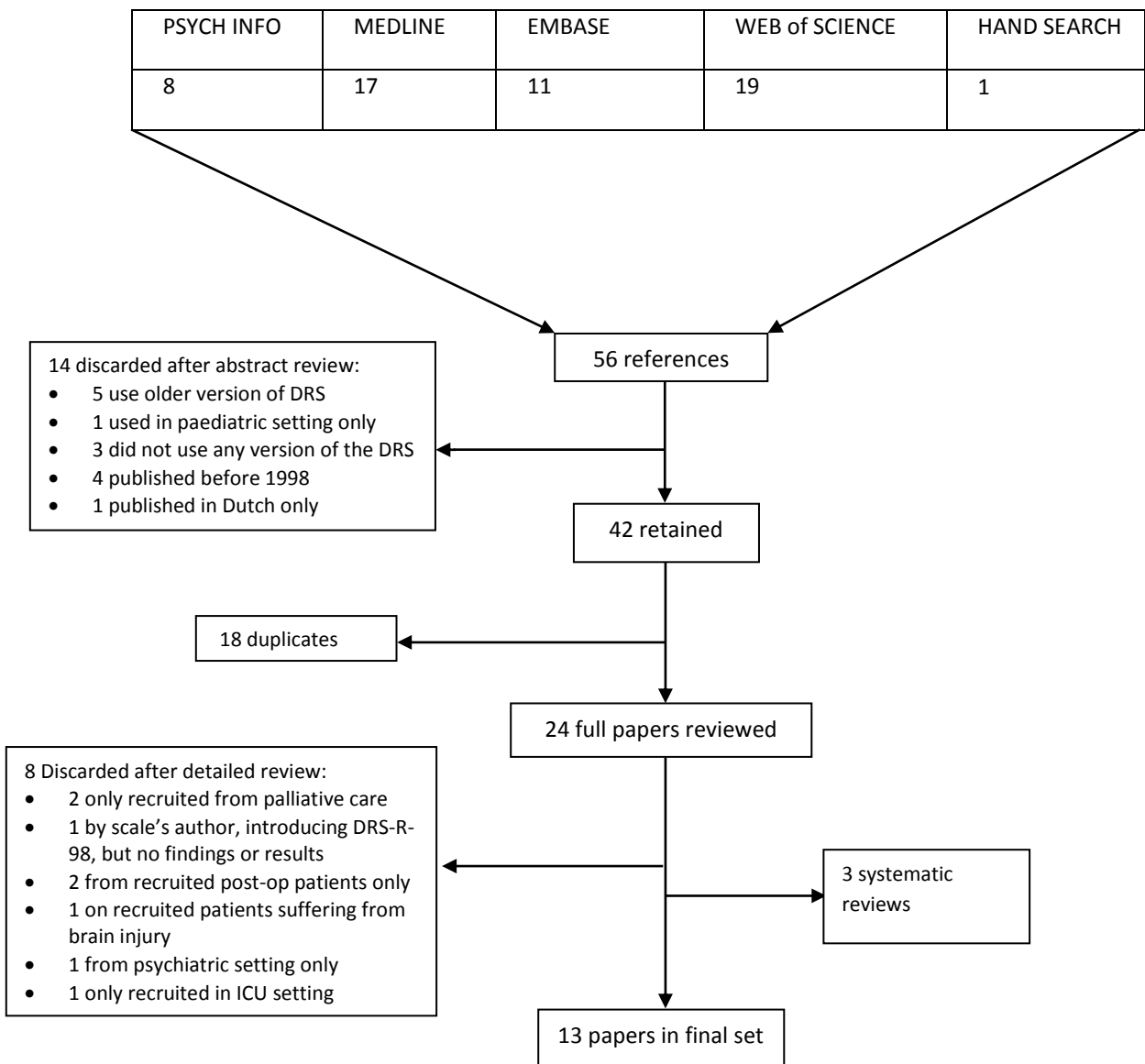
AND

Sensitivity OR Specificity OR Efficacy OR Reliability OR Validity

Papers found: 19

	Search Terms	MEDLINE	EMBASE	PSYCHINFO
1	Delirium Rating Scale OR DRS- R -98	102	174	160
2	Delirium OR Dementia OR Psychotic OR Psychosis	69254	182944	91697
3	Aged OR 'Aged, 80 and over' OR Elder\$ OR Older person\$	1604509	403307	74075
4	Impatient\$ OR Acute Disease OR Acute Illness OR Hospital\$	573540	1276395	109794
5	Sensitivity OR Validity OR Specificity OR Efficacy OR Reliability	1000247	1971115	272144
6	1 and 2 and 3 and 4 and 5	17	11	8

**Figure 2: Identification and selection of papers**



The 13 remaining studies were read and the relevant data extracted. (See appendix 2).

**4.3.2 Sample:** The samples in the studies reviewed were between 30 and 161 participants. The age ranges within the papers varied greatly as well. Whilst attempting to limit the age range of participants to those 65 years or older, the age ranges in the papers chosen started as young as 16 but did not exclude older participants, so

incorporating a large range of ages. Five studies included participants who were exclusively aged 65 years and older, eleven papers included participants of 20 years and older, and one study had participants who were 40 years and older.

**4.3.3 Recruitment:** Of the thirteen papers, all participants were recruited from in-patient settings. Twelve were based on using those diagnosed with a psychiatric condition according to the Diagnostic and Statistical Manual of Mental Disorders – DSM III-R or DSM IV criteria, and all bar three papers reported that the users of the DRS-R-98 were blinded to this prior diagnosis. The remaining papers do not state whether raters were or were not blinded to the DSM IV diagnosis. Twelve of the papers only started the recruiting process and used the DRS-R-98 after a diagnosis of delirium had already been made. Only two studies screened for potential participants within 48 hours of them being admitted, to see whether they met the criteria for participation.

**4.3.4 Execution of the Scale:** In eight of the thirteen papers, the DRS-R-98 was used by a psychiatrist to identify delirium or measure its symptoms, in two it was by geriatrician, in two a research assistant whose qualifications were not stated and in the final paper it was conducted by a registered nurse.

**4.3.5 Psychiatrists as Raters:** In ten of the papers the DSM III-R or DSM IV was used by a psychiatrist for the initial diagnosis. Only one of the papers stated that the psychiatrist in question was a third party to the study itself and not involved directly.

**4.3.6 Mental Illness:** Four of the papers included participants suffering from schizophrenia or other psychiatric diagnoses (including depression and bi-polar disorders). Five included a control group with no diagnosis of mental illness.

Nine of the papers did include participants suffering from dementia: of these, seven had participants with dementia as part of a comparison group with little or no reference made to the co-morbidity which may exist between dementia and delirium.

One of the papers did not include any comparative groups and participants were recruited only if they had a clinical diagnosis of delirium. This paper was designed to



illustrate the validity and reliability of the DRS-R-98 but could not report any values for sensitivity or specificity so did not examine whether the scale can distinguish delirium from other mental illnesses.

Four papers excluded recruit participants with a known diagnosis of dementia and three of the studies included a sub-group in which the participants were suffering from both delirium and dementia at the time of recruitment.

**4.3.7 Comparator Scales:** Many of the papers included the use of comparative scales and the most commonly used was the Mini Mental State Examination (foreign language translations) which was used to measure levels of cognitive dysfunction in eight of the studies. A variety of other tools were used including the Confusion Assessment Method (CAM), IQCODE, and the original version of the DRS. However the use of such tools was so varied between papers, as to which ones were employed and how many were used, that the results between the papers were highly heterogeneous and therefore non comparable. In one paper the DRS-R-98 was used as a 'gold standard' to assess the DOM scale.

**4.3.8 Prior Formal Diagnosis:** In two of the papers participants were given a formal diagnosis before the tool was used. As delirium can be undiagnosed in general hospitals, this pre-screening may have led to the identification of milder cases which clinical identification was more likely to miss. In one of the papers it is also mentioned that researchers were not blinded to the diagnosis prior to using the DRS-R-98. If the rater is already aware of the nature of the mental illness of the patient this could have led to information bias, as the items would have been scored with prior knowledge of the final diagnosis.

**4.3.9 Co-Morbidity:** In only three of the papers were diagnoses of delirium superimposed on dementia measured and analysed. Due to the incidence of their co-morbidity in older populations, the three papers which included these items may be able to provide true values for specificity and sensitivity in the general hospital population due to the inclusion of this category. However, in one of these three studies

the specificity and sensitivity were not reported. In one of the papers participants with delirium superimposed on dementia was noted and compared with dementia and delirium only groups.

**4.4 SETTINGS IN WHICH THE DRS-R-98 HAS BEEN USED:** Twelve of these papers were conducted in general hospitals, although four of them also included participants recruited from the psychiatric wards of these hospitals and three included recruitment from rehabilitation and outpatient wards as well. One recruited from geriatric medical wards.

#### **4.5 EVIDENCE OF VALIDITY:**

**4.5.1 Content validity:** Nine of the thirteen papers support the face and content validity that the DRS-R-98 may have.

**4.5.2 Concurrent validity:** The association between the DOM and DRS-R-98 was analysed using Spearman's rho and found to be 0.80. The Pearson correlation between the DOS and DRS-R-98 was 0.61. Negative correlations between MMSE and the DRS-R-98 were shown in six papers and Pearson correlations were shown to be between 0.64 and 0.70 thus indicating that the DRS-R-98 was identifying impairment in cognitive function.

**4.5.3 Sensitivity and specificity:** The specificity and sensitivity of the DRS-R-98 was compared with clinical diagnosis, and was noted in eight of the papers. Six papers noted a sensitivity ranging from 86% to 98% and specificity ranging from 72% to 77% when the DRS-R-98 was used to distinguish delirium from other mental health problems. When a sample consisting of only those suffering from delirium, dementia and delirium superimposed on dementia was used, sensitivity ranged from 56% to 93% and specificity ranged from between 75% and 95%.

In one study, items of the DRS-R-98 were used to identify sub-types of delirium. Here it was found that when combined, the sensitivity and specificity for items 4 (lability of affect) and 7 (motor agitation) for non-hypoactive delirium were 89% and 57% respectively.

**4.5.4 Construct validity:** In seven of the studies the internal consistency of the DRS-R-98 was analysed using Cronbach's alpha to measure the intercorrelations among the test items. The scores were found to be between 0.76 and 0.94 indicating that there was high degree of internal consistency and the items in the DRS-R-98 were measuring the same thing.

**4.5.5 Sensitivity to change:** In two of the studies the DRS-R-98 was used to measure the improvement of delirium throughout treatment. In both cases where delirium had resolved there was a significant change in DRS-R-98 score. In one of these studies the mean score was noted to change from 21.5 at baseline to 5.2 once resolved ( $P < 0.001$ ).

**4.5.6 Reliability:** The inter-rater reliability (IRR) was recorded in seven of the studies. Intra Class Correlation Coefficients (ICCs) were documented in seven papers to assess this and were reported as ranging between 0.92 and 0.98 showing that there was a high degree of agreement between the raters' scoring.

#### **4.6 DISCUSSION:**

The literature search found thirteen papers which were relevant to the aims of the review.

**4.6.1 Validity:** The papers identified by the search indicate that there is evidence that the DRS-R-98 is a sensitive and specific tool. Although some of the literature suggests that the DRS-R-98 might lose some of its specificity and sensitivity when the participant sample includes those suffering from delirium and dementia there remains some evidence that the DRS-R-98 scores are still significantly higher in those with delirium, despite prior cognitive impairment.

This is pertinent to the search as papers that show the DRS-R-98 was able to demonstrate high sensitivity and specificity in patients suffering from both conditions (both of which can alter cognitive ability) and provide evidence to suggest that the scale is not only valid and capable of measuring delirium but can also differentiate it from other mental illnesses.

**4.6.2 Applicability:** All the papers were selected on the basis that participant recruitment was conducted in general hospital and not exclusive to psychiatric, palliative or intensive care wards. This should mean that the reported findings are applicable to general hospital wards.

**4.6.3 Users:** Many of the scale users in the papers selected were either psychiatrists or geriatricians who are likely to be familiar with identifying the features described in the DRS-R-98. While not directly biasing the results, the prior training received by these raters could have implications for how the scale may be used to identify delirium for non-research purposes. Not all general hospital wards may offer much patient contact with such specialists and other members of a multidisciplinary team may not be able to use the DRS-R-98 to identify symptoms of delirium, or the syndrome with the same level of accuracy.

**4.6.4 Sensitivity to change:** By including two studies in which the DRS-R-98 was used to rate delirium throughout a course of treatment, this supports the scale's criterion validity. As the DRS-R-98 scores reduce during the treatment, it shows that the DRS-R-98 is measuring the severity of the delirium as it was intended.

**4.6.5 Concurrent Validity:** One of the papers used the DRS-R-98 as a scale by which to validate a different scale. There was a significant correlation between the DOS and the DRS-R-98. As both scales were designed to measure delirium this supports the concurrent validity of the DRS-R-98.

**4.6.6 Discriminant Validity:** Two of the papers identified by the search analysed the data from not only patients with and without delirium but also included in their participant sample those who also had a diagnosis of another mental health problem.

**4.6.7 Franco et al. (2009):** conducted a factor analysis of the DRS-R-98. Data from three groups was analysed. The patient participants were distinguished by their DRS-R-98 scores; a 'non-delirium' group (scoring between 0 and 7 on the DRS-R-98), a 'subclinical/prodromal delirium' group (scoring between 8 and 13) and a 'delirium'

group (scoring 14 or more) within the first 24 hours of their hospital admission. There was a diagnosis of dementia in 5 of the patients in the subclinical/prodromal group, 6 of the delirium group and 2 of the non-delirium group. The different items of the DRS-R-98 were analysed and the scores of 9 of the 16 items of the scale were found to be significantly different across all 3 groups, with scores being higher in the delirium group than the other groups. This study supports the construct validity of the DRS-R-98, as demonstrated by the factor analysis conducted (in which all 16 items were significantly different between the delirium and non-delirium groups) and shows that the DRS-R-98 measures core symptoms (such as sleep/wake abnormalities) and that these had high correlations with associated symptoms (such as temporal onset). The scores for each criteria were higher in those participants who were split into the 'delirium' group than in those in the 'prodromal' or 'non-delirium' groups. Due to the significant differences in scores between the groups, evidence was provided to support the criterion validity of the DRS-R-98.

The authors reported that no specific evaluation of dementia in participants was conducted at recruitment nor was a pre-delirium evaluation of patients' cognitive function performed. Instead, those accompanying participants into hospital on admission were asked if any history of dementia or dementia symptoms had been noted. However, it is not reported as to whether these informants were asked to provide any evidence on delirium or symptoms of delirium which may have occurred.

**4.6.8 Andrew et al. (2009):** split patient participants into groups according to cognitive diagnoses as well as having a diagnosis of delirium or not. Dementia and delirium were diagnosed and patients were identified as having either 'cognitive impairment, no dementia' (CIND), 'no cognitive impairment' (NCI), dementia, delirium, delirium superimposed on CIND and delirium superimposed on dementia. The evaluations were conducted by two independent raters (within 1 hour of each other) one of whom was a geriatrician with prior experience of diagnosing delirium so clinical co-morbidities of patients with delirium could be taken in to account independently. Patients with NCI had the lowest scores, while patients with delirium had the highest

scores. However, the DRS-R-98 was found to have low sensitivity (0.59) and specificity (0.67) between the dementia and delirium groups. Eleven patients with no delirium were found to have DRS-R-98 scores of above the cut-off of 17.75. Of these patients three had suffered from a stroke, three had Alzheimer's disease and three had other or unspecified dementia. This could indicate that the scale may not be able to distinguish delirium from other mental health problems and does not have criterion validity. However, it was noted that the mean DRS-R-98 scores did differ between the delirium superimposed on dementia group (20.2 with 95% confidence interval of 16.1–24.3) and the dementia group (14.1 with 95% confidence interval of 10.7–17.4). This illustrates that the DRS-R-98 may be used to identify delirium in a patient suffering from dementia as well as distinguish between the two conditions, however as the confidence intervals overlap this is not certain.

Andrew et al reported that the specificity and sensitivity of the scale were moderate, highlighting the difficulty of distinguishing delirium from other mental health problems. However, the authors noted that the clinical assessments which were used to identify dementia, and the identification and measurement of delirium symptoms using the DRS-R-98 were not always carried out on the same day. They also reported that despite some loss of sensitivity and specificity, the DRS-R-98 had high IRR and good construct validity (shown by the significant correlations between items rating symptoms using patients' behaviour and items rating symptoms using patients' histories and medical notes).

**4.7 WEAKNESSES IN THE LITERATURE:** The validity of the DRS-R-98 has not been widely studied. The main barriers to establishing the validity of the DRS-R-98 appeared to be that only few studies included sample groups that contained patients suffering from delirium and mental health problems, with the main focus being on patients who were suffering from delirium only. Patient participants with dementia appeared to be recruited into comparison groups rather than in the 'delirium' groups, despite associations and known risk of comorbidity of the two conditions. In 7 of the papers, users of the DRS-R-98 were psychiatrists, who would have received specialist training.

Only 2 of the papers included non-clinician scale users. The DRS-R-98 itself includes standard instructions to guide assessment, which could be validated if assessors did not have prior psychiatric training to assist them in identifying symptoms on the scale.

**4.8 LIMITATIONS OF THE STUDY:** The search found a small number of papers. This could be due to the search terms being too restrictive and the subject being too narrowly defined, or to the possibility that there are not many papers which directly explore the validity of the DRS-R-98. References of selected papers were analysed and papers known to the author considered, ensuring that key papers were not missed.

#### **4.9 CONCLUSION:**

Findings of the systematic review suggest there is a range of evidence available which report that the DRS-R-98 is a valid scale and therefore suitable for identifying and measuring delirium. However, further research is needed in which:

- Formal diagnoses of other mental health problems, as well as delirium and control groups should be recorded for the entire participant population. Few validation studies for the DRS-R-98 appear to use patient participants suffering from both delirium and dementia, despite associations identified in previous research.

- Patient participants should be selected systematically from a general hospital population, as cases of delirium may go undetected and use of DRS-R-98 in this participant group may highlight issues with sensitivity and specificity.

- Patient participants should have informants who are able to report delirium or delirium symptoms prior to the admission. The papers identified do not report the use of informants despite the scales author noting the use of caregivers and visitors during data collection.

- Studies need to be done which identify patients early in their admission, when screening or diagnostic scales are likely to be of most use clinically.

As the DRS-R-98 appears to be an appropriate tool to diagnose delirium and distinguish it from other mental health problems, the next stage of this thesis was to analyse data where it had been used to detect delirium in a cohort of older people with mental health problems. From this, the features and outcomes associated with having delirium were identified.



## **5 METHOD:**

**5.1 PRIMARY OBJECTIVE:** To establish whether the DRS-R-98 is able to distinguish delirium from other mental health problems in a general hospital population.

### **5.1.1 Secondary Objectives:**

-To examine the association between DRS-R-98 scores, demographic variables and health problems in older people admitted to general hospital as an emergency.

-To examine if DRS-R-98 scores are associated with outcomes.

### **5.2 STUDY DESIGN:**

The research questions were answered drawing from data from the MCOP-BMH study, conducted between 2009 and 2010. As the aim of this thesis was to assess the use of the DRS-R-98 in a population of older people with mental health problems and analyse the associated factors and outcomes of older patients with delirium, this data was to seen to be appropriate. The aim of MCOP-BMH was to measure the prevalence and severity of mental health problems, including delirium as measured by the DRS-R-98 in older people admitted to general hospital as an emergency (Gladman et al. 2012).

The MCOP-BMH study measured health status of patient participants at baseline, including the DRS-R-98, (two to five days after admission) and a range of outcomes 6 months later.

A two-stage assessment procedure was used. The first stage identified and excluded people who were unlikely to suffer from mental health problems. The second stage involved patients and their carers completing a battery of questionnaires designed to measure both their physical and mental health status.

### **5.2.1 Screening:**

Consecutive admissions to study wards were approached between two and five days of their hospital admission. The screening was conducted by three researchers (a geriatrician, psychologist and nurse) on twelve wards (two trauma orthopaedic, three acute geriatric medical and seven general medical) in the Queens Medical Centre and Nottingham City Hospitals Campuses of Nottingham University Hospitals NHS Trust. These wards were visited in rotation. Verbal consent to answer questions was taken from the potential patient participants. The screening battery included:

- The abbreviated mental test score (AMTS) (used to identify cognitive impairment) (Hodkinson 1972).
- GDS 4 questions (to identify patients exhibiting symptoms of depression) (Kurlowicz and Greenberg 2007).
- PRIME-MD anxiety screen (Spitzer et al. 1999).
- CAGE questions (identifying alcohol abuse) (Ewing 1984).
- A bespoke question was used in cases where the patient had already been diagnosed with a psychiatric diagnosis or if there was any other reason (such as behaviour) to suggest a mental health problem (see appendix 3).

Finally, patients were asked if they would be willing to take part in a further research study regarding mental health problems on hospital medical wards.

### **5.2.2 Inclusion criteria for the MCOP-BMH study:**

- Patients aged 70 years or older.
- Patients admitted to hospital as an emergency to 12 specific wards: 3 acute geriatric medical, 2 trauma orthopaedic and 7 general medical in the Queens Medical Centre and Nottingham City Hospital campuses of Nottingham University Hospitals NHS Trust.

- Patients who screened positive for mental health problems between days 2 and 5 of their admission.
- Patients consented to take part if they had capacity.
- Patients who had a willing carer/family member to provide consultee agreement in cases where participants lacked capacity.

### **5.2.3 Exclusion criteria for the MCOP-BMH study:**

- Non-English speakers without translators.
- Nursing/residential home residents with no unpaid carers to act as an independent consultee or informant.
- Patients where consent or consultee agreement was not obtainable.
- Those with no carers over the age of eighteen years.
- Patients not admitted as an emergency (for example elective surgery).
- Patients who were unconscious.
- Patients not admitted to the pre-specified wards.
- Patients whose clinical team did not believe they would survive the admission (death within 12 days).

### **5.2.4 Patient and carer participants:**

After screening, patients who screened positive for one or more mental health problems were approached to take part in the MCOP-BMH study.

Next, the capacity of the patient to give informed consent was assessed.

-In cases in which patients were deemed to have capacity, information sheets regarding the study and its aims were given to patients and they were asked if they were willing to take part and complete the consent forms. Permission was sought to contact the patient's carer. If permission was given by the patient participant, the closest family member or carer to the patient was identified and attempts were made to contact them by telephone or in person.

-If capacity was not present, information sheets were given to carers and if willing consultee agreement was sought.

Carers were also approached to be recruited as carer participants.

The MCOP-BMH protocol defined a carer as 'someone who sees the patient at least once a week for a minimum of one hour'. This definition allowed the inclusion of spouses, siblings, children and close friends. In cases where there was more than one carer the most available or willing was chosen.

### **5.2.5 Data collection at baseline:**

Demographic data regarding patients were collected from both medical records and interviews and included their age, living arrangements, marital status and the type of ward they had been admitted to (see appendices 4 and 5).

For patient participants at baseline the following scales were completed:

- Delirium Rating Scale -revised version -98 (DRS-R-98) (Trzepacz et al. 1998): to measure the prevalence and severity of symptoms of delirium.
- Modified early warning score (MEWS) (Subbe et al. 2001): measuring the severity of acute illness on admission.
- Study of osteoporotic fractures frailty scale (SOF) (Ensrud et al. 2008): to measure frailty.
- Charlson Index (Charlson et al. 1987): to measure co-morbidities.
- An adapted version of the Neuropsychiatric Inventory (NPI) (Cummings et al. 1994): to ascertain the presence of behavioural and psychological features associated with mental health problems.
- Cornell Scale for Depression in Dementia (CSDD) (Alexopoulos et al. 1988): to diagnose symptoms of depression and measure its severity.
- Mini mental state examination (MMSE) (Folstein et al. 1975): to measure cognitive function.

- Barthel index (Mahoney and Barthel. 1965): to measure functional ability in activities of daily living at admission and prior to illness.
- EQ5D (Brazier et al. 1996): to measure quality of life.

### **5.2.6 Structured assessment by a psychiatrist or geriatrician:**

Using the same participant population a sub-study was carried out and further assessments were made (see appendices 6 and 7):

- 3 geriatricians (1 consultant, 2 senior trainees) and 3 psychiatrists (1 consultant and 2 trainees).
- Patient selection: a convenience sample was taken depending on the availability of the assessors, but was essentially random.
- 49 psychiatric evaluations were made. 53 geriatric evaluations were made. 9 of the evaluations were conducted using the same patient.
- The assessments were carried out in the same hospital admission that the cohort baseline data was collected, but not on the same day.
- Assessors were asked to make a clinical assessment, at a level consistent with a thorough ward consultation, using notes, questioning of the patient or carers and examination.
- Assessors were asked to research problems, drugs were stopped or started, other interventions undertaken and outstanding needs for intervention.
- Diagnoses of delirium according to DSM IV criteria were made.

### **5.2.7 Data collection at 180 day follow-up:**

Patient and carer participants were included in the study for a maximum of 180 days.

Data were collected either:

- During a home-visit (the arrangement of which was attempted for each patient participant).

- By telephone with carer of patient.
- By telephone with the patient's General Practitioner.
- Through the NUH NOTIS computer system to collect data regarding hospital admissions during the 180 days or up to date of death.

Data collection at 180days:

- Ascertainment of death.
- Length of stay in hospital.
- Number of hospital admissions.
- Number of days at home.
- Institutionalisation.

Data collection conducted by a researcher during a home visit included:

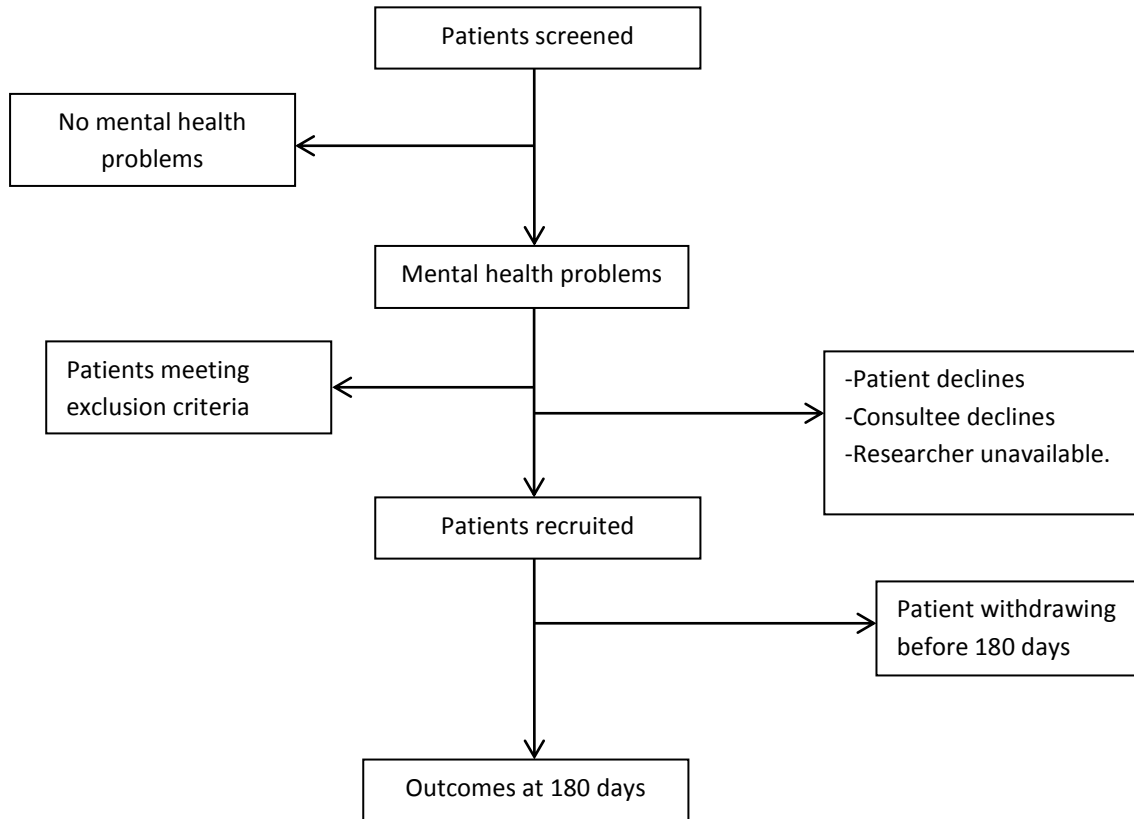
- Mortality.
- MMSE (Folstein et al. 1975).
- Quality of life using the DEMQoL (Smith et al. 2005)
- Quality of life using EQ5D scales (Brazier et al. 1996).
- Basic ADL: Barthel Index (Mahoney and Barthel. 1965).
- An adapted version of the Neuropsychiatric Inventory (NPI) (Cummings et al. 1994)
- Social and health care: Client Services Receipt Inventory (including readmission to hospital) (Beecham and Knapp. 1992).

(See appendix 8)

### **5.2.8 Withdrawal:**

Patient and carer participants were informed in the information sheets that they had the option to withdraw from the study at any time but that any data collected prior to the withdrawal would not be destroyed and could still be used in the data analysis after the rest of the data collection was complete.

**Figure 3: Recruitment procedure**



**5.2.9 Training of researchers:**

- Training in the use of the scales was provided by the consultant geriatrician.
- Consistent training and performance reviews were conducted to ensure both initial and 180 day outcome questionnaires were carried out in a reliable, uniform manner.

**5.2.10 Confidentiality:**

- All patient and carer participants were allocated a study ID number so that their anonymity could be maintained.
- Hard copies of data were stored in locked filing cabinets.
- All electronic data were stored in a password protected Access database.

**5.3 DATA MANAGEMENT:** Data was entered onto an Access database and extensively checked manually and using range and consistency checks. In keeping with the scoring manual missing or unavailable items for the DRS-R-98 were scored as 1.5.

#### **5.4 DATA ANALYSIS:**

**5.4.1 General considerations:** Analyses were carried out using STATA version 11. As part of the data analysis, DRS-R-98 scores were used as a continuous variable but a pre-specified sub-group analysis was also considered. The population was split according to the recommended DRS-R-98 cut-off of 17.75 (Trzepacz et al. 2001) to identify those likely to have delirium or not. The DRS-R-98 scores were also divided into quartiles creating an ordered categorical variable. This enabled tests for trend to be performed, as well as allowing the comparison of the highest and lowest quartiles.

**5.4.2 Baseline data:** Descriptive statistics of the data were presented including an item response analysis and associations between this data and DRS-R-98 scores identified. This explored what the DRS-R-98 may measure and the associations of what these scores may mean for an older patient.

For each categorical variable, uni-variate analysis was carried out, producing crude odds ratios. Logistic regression was then carried out in order to produce 95% confidence intervals, and allowed the odds ratio to be adjusted for confounding variables (identified during data analysis).

Continuous variables were described using means if the data was normally distributed and medians if it was not. Where these variables were normally distributed linear regression was performed. If not, the data was either transformed, or the median of the variable taken and used instead.

**5.4.3 Outcome data:** From the outcome datasets, all outcome variables were analysed. Descriptive statistics were presented on the outcomes data, including variables such a mortality rate, new care home placement and length of any hospital



admissions after recruitment. The reassessment of functional and cognitive ability allowed the analysis of whether there is an association between DRS-R-98 score and disability. Differences in Barthel scores and MMSE totals between baseline and outcome were noted as separate variables.

Categorical variables were subject to uni-variate analysis producing crude odds ratios. Logistic regression was then carried out in order to produce 95% confidence intervals, and adjusted odds ratios.

Continuous variables were described using means or medians according to whether the variable was normally distributed or not. Where variables were normally distributed linear regression was performed. If not, the data was transformed.

**5.4.4 Participants with incomplete data:** Once the analysis of the baseline data was complete, and before exploratory analysis of the outcome data was conducted, comparisons were made between those participants who were not available to collect a full dataset at follow up (due to ill health, refusal to follow-up or death) and those who were. Baseline characteristics were compared to see if there were any significant differences between the groups. Due to some of the data being made available over the telephone participants at this stage were split into groups:

- Participants from whom a full data set was collected.
- Participants from whom only part of the dataset was collected.
- Participants from whom there is no data except that regarding hospital admissions to Nottingham University Hospitals, mortality status and CSRI.
- Participants for whom, at outcome, no data could be collected.

**5.4.5 Population:** The characteristics of the full participant population were described and both baseline and outcome data analysed. Once this was done the descriptive statistics were stratified according to presence of delirium as identified by the DRS-R-98. Associations between demographics or health problems and DRS-R-98 scores were explored, including any associations between the DRS-R-98 and participant's living

arrangements, age, gender, functional disability, frailty and other mental health problems.

**5.4.6 Scale performance:** Item analysis was conducted. The number of missing items was noted and distributions of the scores analysed. The internal consistency of the DRS-R-98 was calculated using Cronbach's alpha coefficients. A high score would indicate that the DRS-R-98 has good internal consistency and that all the items were measuring the presence or absence of delirium.

**5.4.7 Validity:** A primary objective was to establish whether the DRS-R-98 was a valid scale, able to distinguish delirium from other mental health problems in older patients in a general hospital population.

**5.4.7.1 Criterion validity:** The criterion validity was investigated by comparing DRS-R-98 scores of participants against a 'gold standard'. Independent psychiatric and medical assessments were conducted on a sample of the cohort population, including diagnoses or absence of delirium. It is from these that the sensitivity and specificity of the DRS-R-98 was calculated. A ROC curve was also produced to show whether the DRS-R-98 was able to differentiate between delirium and no delirium and the cut-off points examined. The published cut-off of 17.75 was tested using ROC curves.

We assumed that patients with an improvement in their cognitive function over 6 months were likely to have had delirium (Meagher 2001) and tested the DRS-R-98 with this as the gold standard comparator. MMSE scores of those who were identified as having delirium or not by the DRS-R-98 were analysed. Recoverable cognitive function has been previously defined as an increase of 3 or more on the MMSE (Inouye et al. 2006).

**5.4.7.2 Predictive validity:** This was investigated by analysing the mortality rates according to DRS-R-98 score. MMSE scores at baseline and outcome were analysed. As the cognitive impairment caused by delirium can be reversible, a higher DRS-R-98

score and an increase in MMSE at outcome could help to identify in which cases the scale may have demonstrated predictive validity.

**5.4.7.3 Construct validity:** Construct validity was assessed by analysing the associations between DRS-R-98 scores with other scales measuring related variables.

The Study of Osteoporotic Fractures frailty scale (SOF) was used as a measure of frailty. Delirium may be linked to frailty in older people. An association between high DRS-R-98 and high SOF scores may have shown that the DRS-R-98 may be detecting delirium and a predisposing factor.

The Modified Early Warning Score (MEWS) was used as a measure of severity of acute illness on admission. Delirium is associated with an acute physical illness. If cognitive deficits perhaps caused by delirium (as measured by the DRS-R-98) have developed due to levels of illness (as measured by the MEWS), it may help to show that the DRS-R-98 has a concurrent validity with the MEWS and that the DRS-R-98 is associated with a key factor of the syndrome.

The Charlson Index was used to measure co-morbidities. Older people may be more vulnerable to the development of a delirium due to more frequent levels of physical illness. As the Charlson Index measures previously diagnosed illnesses (prior to the index admission), an association with the Charlson may have shown that the DRS-R-98 may be measuring delirium, which due to previously diagnosed illnesses have left the patient more susceptible to the syndrome. The Charlson also records a previous diagnosis of dementia and thus allowed comparisons to be made between patients with dementia, with delirium, with delirium and dementia and with neither delirium nor dementia.

The Neuropsychiatric Inventory (NPI) was used to capture any data regarding the presence of behavioural and psychological features associated with mental health problems. As the DRS-R-98 has items which also measure behavioural and psychological symptoms associated with delirium such as perceptual disturbances, delusions, disturbances to motor function and sleep-wake patterns, an association

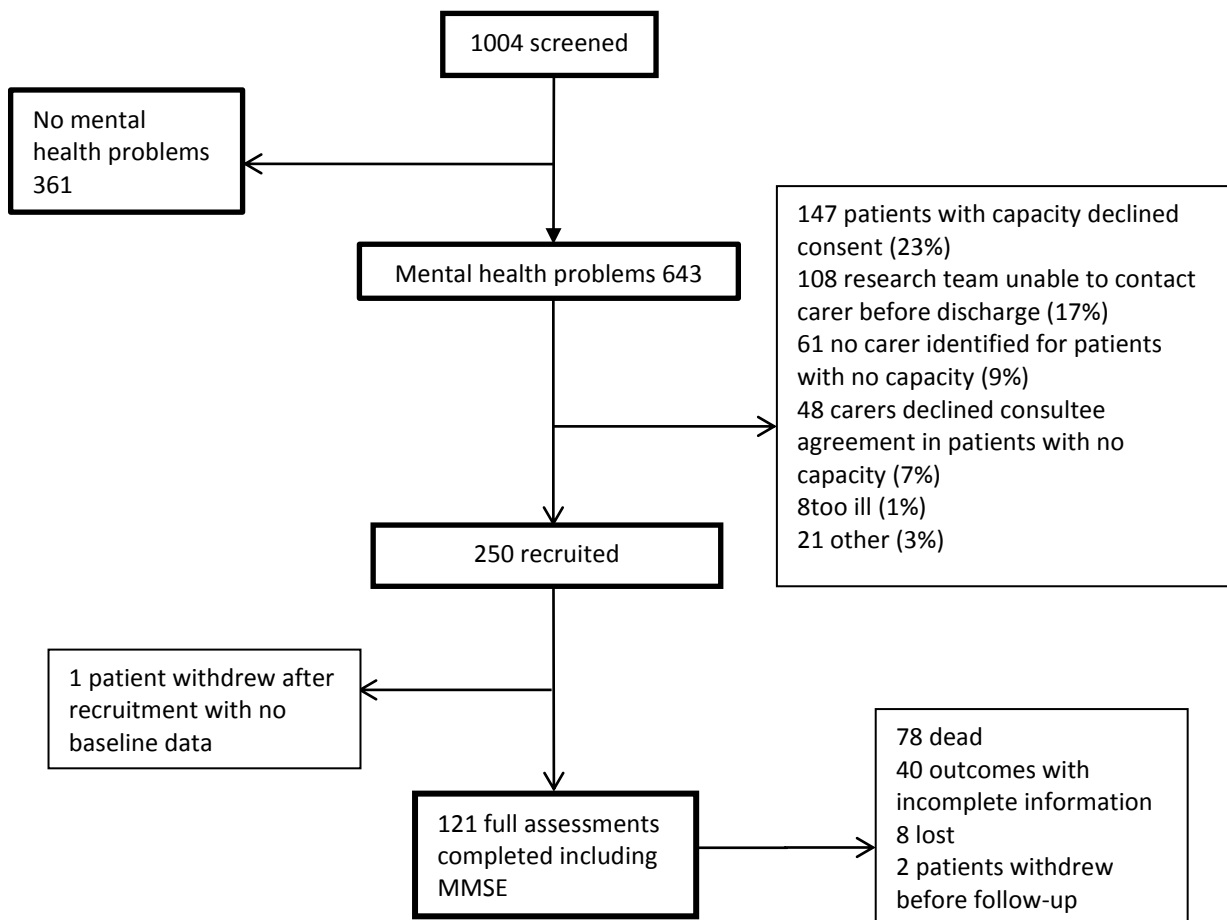
between the two scales could indicate that these symptoms are being detected by the DRS-R-98.

The number of medications was recorded at baseline. As delirium has been associated with polypharmacy an association between the two variables could have supported the construct validity of the DRS-R-98.

## 6 RESULTS

**6.1 RECRUITMENT:** The three researchers recruited 250 participants between the 4<sup>th</sup> April 2009 and 3<sup>rd</sup> November 2009. 1004 patients were screened, 361 (36%) were unlikely to have mental health problems. From the remaining 643 (64%) 250 were recruited. One participant withdrew before the baseline data could be collected. At 180 day follow-up, an outcome questionnaire was completed by 121 (49%) participants. Of the outcomes questionnaires which were not completed, 78 (31%) participants had died, data regarding 20 (8%) participants could only be collected by-proxy from carers, data regarding 20 (8%) was incomplete due to patients' ill health or refusal to a follow-up visit, 8 (3%) were lost to follow-up and a further 2 participants (1%) had withdrawn.

**Figure 4: Recruitment**



## **6.2 BASELINE DATA:**

**6.2.1 Demographics:** The median (IQR) age of patients recruited was 84 (79-89), 66% were female and had been admitted to hospital from either their own home (79%) or a care home (21%). 47% of the participants were recruited from acute geriatric medical wards, 34% from acute medical wards and 18% from trauma orthopaedic wards.

**6.2.2 Physical health problems:** Table 1 shows the levels of functional disability of the cohort, as measured by the Barthel index. Prior to the admission participants with delirium (according to the DRS-R-98) had significantly lower levels of functional ability than participants who did not ( $P < 0.001$ ): 64% of participants with delirium had Barthel scores of 0-5, versus 36% who did not. Of the more functionally able participants, with Barthel scores of 16-20, 29% had delirium, versus 71% who did not.

Table 1 shows that the functional ability in the participants was worse by the time of admission and that participants with delirium continued to be more dependent than those who did not. 64% of participants with a Barthel score of 0-5 also had delirium. Of the more functionally able participants, 15% had delirium, versus 85% who did not.

There no was significant association between the number of medical conditions the participants suffered from and whether they had delirium ( $P = 0.36$ ).

There was no relationship between frailty (measured by the SOF) and delirium as 52% of those in the least frail category had delirium but 52% in the frailest category also had delirium.

The number of medications was recorded and the median (IQR) number of medications the patients were prescribed to take was 7 (4-9) (6 for those with delirium as opposed to 7 for those without).

There was no relationship between levels of acute illness on admission and delirium. Median (IQR) early warning scores taken on admission were 1 (1-2) (1 for participants with delirium and 1 for those without).

There was no significant association between quality of life and delirium. The median EQ5D (IQR) score was 0.18 (-0.4 – 0.3) (0.2 for those with delirium and 0.17 for those without).

**Table 1: Characteristics of full study population**

		Total	Delirium N=107	No delirium N=142	P value
Age (n=249)	Median (IQR)	84 (79-89)	86 (80-89)	83 (78-87)	0.36
Female (n=249)	n (%)	165 (66)	63 (68)	93 (66)	0.76
Accommodation (n=249) n (%)	Care home	52 (21)	43 (40)	9 (6)	<0.001
	Own home n	118 (47)	34 (31)	84 (59)	
	Own home with carer	79 (32)	30 (28)	49 (35)	
Prior Barthel Index (n=244) n (%)	0-5 n	14 (6)	9 (9)	5 (4)	<0.001
	6-10	33 (14)	23 (22)	10 (7)	
	11-15	58 (24)	32 (31)	26 (19)	
	16-20	139 (57)	40 (38)	99 (70)	
Admission Barthel Index (n=249) n (%)	0-5 n (%)	66 (27)	45 (42)	21 (15)	<0.001
	6-10	74 (30)	35 (33)	39 (27)	
	11-15	68 (27)	21 (20)	47 (33)	
	16-20	41 (16)	6 (6)	35 (25)	
Charlson Comorbidity (n=249) n (%)	0-1 n (%)	76 (31)	31 (29)	45 (32)	0.36
	2-3	104 (42)	50 (47)	54 (38)	
	4+	69 (28)	26 (24)	43 (30)	
SOF frailty (n=248) n (%)	0-1	50 (20)	26 (25)	24 (17)	0.05
	2	144(58)	52 (49)	92 (65)	

	3	54 (22)	28 (26)	26 (18)	
Medications (n=241)	Mean (IQR)	7 (4-9)	6 (5-9)	7 (5-10)	0.177
MEWS (n=249)	Median (IQR)	1 (1-2)	1 (1-2)	1 (1-2)	0.65
EQ5D (n=248)	Median (IQR)	0.18 (-0.4 - 0.3)	0.79 (-0.1 - 0.3)	0.2 (0.04- 0.6)	0.177

*IQR Inter quartile range*

*SOF Study of osteoporotic fractures frailty scale*

*MEWS Modified early warning score*

There was no significant correlation between DRS-R-98 scores and levels of physical illness on admission as measured by the MEWS.

There was no significant association between DRS-R-98 scores and the number of medications the patients were prescribed on admission.

Chi squared tests were conducted and showed that a positive score for delirium on the DRS-R-98 was significantly associated with admission to hospital from a care home being functionally disabled and having increased levels of frailty.

**6.2.3 Mental health problems at baseline:** Table 2 shows the mental health problems experienced by the population. In this thesis delirium was identified using the recommended DRS-R-98 cut-off of 17.75. 107 (43%) patients scored positively for delirium according to the DRS-R-98.

106 (43%) of the patients had a diagnosis of dementia (68% of whom had scored positively for delirium on the DRS-R-98).

There was a significant association ( $P < 0.001$ ) between cognitive impairment (as measured by the MMSE) and DRS-R-98 score. Of the participants with severe cognitive impairment (MMSE of 0-9), 88% had delirium. All of the participants (100%) who had delirium had a cognitive impairment ( $MMSE \leq 25$ ).



There was a relationship between depression and delirium. 40% of the patients suffered from mild depression (as measured Cornell scale for depression) (of which 44% had delirium). 13% suffered from marked depression (of who 67% had delirium).

The median neuro-psychiatric inventory (IQR) score was 24 (14-35) (33 for those also scoring positively for delirium and 20 for those scoring negatively).

**Table 2: Mental health problems at baseline**

		Total	Delirium N=107	No delirium N=142	P value	
Diagnosed dementia (n=249) n (%)	Yes	106 (43)	72 (68)	34 (32)	<0.001	
MMSE (n=248) n (%)	0-9	67 (27)	59 (55)	8 (6)	<0.001	
	10-20	92 (37)	44 (41)	48 (34)		
	21-24	47 (19)	4 (4)	43 (30)		
	≥25	42 (17)	0 (0)	42 (30)		
DRS-R-98 (>17.75) (n=249) n (%)	Delirious	107 (43)				
Dementia and delirium (n=249) n (%)		72 (29)				
CSDD (>10) (n=249) n(%)	Mild Depression CSDD (11-18)	99 (40)	44 (41)	55 (39)	0.003	
	Major Depression (≥19)	33 (13)	23 (22)	11 (8)		
NPI (severity – moderate to marked) (n=249) n (%)	Delusions	31 (12)	27 (25)	4 (3)	<0.001	
	Hallucinations	25 (10)	17 (16)	8 (6)	<0.001	
	Agitation and aggression	35 (14)	32 (30)	3 (2)	<0.001	
	Depression	85 (34)	45 (42)	40 (28)	0.022	
	Anxiety	85 (34)	44 (41)	41 (29)	0.048	
	Elation	3 (1)	2 (2)	1 (1)	0.4	
	Apathy	83 (33)	54 (51)	29 (20)	<0.001	
	Disinhibition	19 (8)	16 (15)	3 (2)	<0.001	
	Irritability	44 (18)	29 (27)	15 (11)	<0.001	
	Psychomotor activity	42 (17)	31 (29)	11 (8)	<0.001	
	Sleep problems	83 (33)	39 (37)	44 (31)	0.34	
	Appetite or eating problems	113 (46)	55 (52)	58 (41)	0.08	
	NPI total (n=249)	Median (IQR)	24 (14-35)	33 (20-52)	20 (11-27)	0.02

MMSE Mini Mental State Examination  
 DRS Delirium Rating Scale –Revised – 98  
 CSDD Cornell Scale for Depression in Dementia  
 NPI Neuro psychiatric inventory

The NPI was used to measure psychiatric symptoms and behavioural problems, some of which the DRS-R-98 also measured. Chi<sup>2</sup> tests were performed and NPI items for delusions, hallucinations and psychomotor behaviours as well as the total NPI scores were significantly associated with scoring positively for delirium.

**6.3 OUTCOMES AT 180 DAYS:** At 180 days 78 (31%) of the patients had died. The median (IQR) number of days spent in hospital was 15 (6-35) and the median (IQR) number of re-admission was 0 (0-1). 19% of participants had moved into a care home after their index admission. Mortality, days spent in hospital and institutionalisation were not found to be significantly associated with delirium.

On 180 day outcome 39 (28%) of the patients had a Barthel score of 0-5, 29 (21%) had a Barthel score of 6-10, 33 (23%) had a Barthel of 11-15 and 40 (28 %) had a Barthel of 16-20. It was found that between baseline and outcome 22% of the patients had a decrease in Barthel score of 3 points or more. A relationship between functional ability and delirium at outcome was found but there was no significant association between a change in dependency between admission and outcome.

**Table 3: Outcomes at 180 days**

		Total	Delirium	No delirium	P value
Mortality at 6 months n (%) (n=249)	Alive	169 (68)	66 (62)	103 (73)	0.19
	Dead	78 (31)	40 (37)	38 (27)	
Length of stay in hospital (n=249)	Median (IQR) (days)	15 (6-35)	14 (7-32)	16 (6-39)	0.56
Hospital re-admissions (n=247)	Yes (%)	104 (42)	45 (42)	59 (42)	0.92
	No (%)	143 (58)	61 (58)	82 (58)	
Moved to Care Home from community (n=247)	Yes (%)	46 (19)	20 (19)	26 (28)	0.93
	No (%)	201 (81)	86 (81)	115 (82)	
Outcome Barthel Index n(%) (n=141)	0-5	39 (28)	22 (40)	17 (20)	<0.001
	6-10	29 (21)	17 (31)	12 (14)	

	11-15	33 (23)	12 (22)	21 (24)	
	16-20	40 (28)	4 (7)	36 (42)	
Decrease Barthel Index of $\geq 3$ (n=141)	Yes (%)	30 (22)	15 (50)	15 (50)	0.16
Increase Barthel Index of $\geq 3$ (n=141)	Yes (%)	45 (32)	14 (25)	31 (36%)	0.19
	No (%)	96 (68)	41 (75)	55 (64)	

There were no significant associations between DRS-R-98 score and mortality or length of stay during index admission.

Barthel score at outcome was significantly associated with delirium but no relationship in the recovery or worsening of dependency.

**6.3.1 Mental health problems at 180 days:** At 180 days it was found that cognitive impairment (as measured by the MMSE) was significantly associated with delirium.

**Table 4: Mental health problems at 180 days**

		Total	Delirium	No delirium	P value
Outcome MMSE (n=121) n (%)	0-9	31 (26)	22 (47)	9 (12)	<0.001
	10-20	37 (31)	15 (32)	22 (30)	
	21-24	17 (14)	5 (11)	12 (16)	
	$\geq 25$	36 (30)	5 (11)	31 (42)	
Increase of MMSE by 3+ (n =121) n (%)	Yes	40 (33)	20 (43)	20 (27)	0.07
	No	81 (67)	27 (57)	54 (73)	
NPI (severity – moderate to marked) (n=121) n (%)	Delusions	15 (13)	11 (19)	4 (6)	0.03
	Hallucinations	8 (7)	7 (12)	1 (2)	0.02
	Agitation and aggression	19 (16)	12 (21)	7 (11)	0.12
	Depression	17 (14)	10 (17)	7 (11)	0.32
	Anxiety	21 (18)	13 (23)	8 (13)	0.16
	Elation	2 (2)	2 (4)	0 (0)	0.13
	Apathy	37 (31)	20 (36)	17 (27)	0.28
	Disinhibition	5 (4)	3 (5)	2 (3)	0.54
	Irritability	14 (12)	10 (18)	4 (6)	0.05
	Psychomotor activity	13 (11)	10 (18)	3 (5)	0.02
	Sleep problems	19 (16)	12 (21)	7 (11)	0.14
	Appetite or eating problems	27 (23)	11 (20)	16 (25)	0.49
NPI total	Median (IQR)	11 (5-25)	13 (7-29)	9.5 (4-22)	0.09

The association between recoverable MMSE and delirium was not significant suggesting that the DRS-R-98 was measuring a more long-term cognitive impairment rather than one that was specific to delirium. As cognitive impairment caused by delirium is resolvable, and there was relationship between cognitive impairment at both baseline and outcome this suggests that the cognitive impairment was present even after the syndrome had resolved.

Four of the twelve NPI scores (delusions, hallucinations, irritability and psycho-motor activity) at outcome continued to have a significant association with baseline DRS-R-98 score. As there was a stronger association between the DRS-R-98 and psychiatric and behavioural problems during index admission than at outcome, this suggests that some of these symptoms may have resolved. This could suggest that the DRS-R-98 detected only psychiatric and behavioural problems associated with delirium. Once the syndrome resolved so did the symptoms, indicating that the problems were resolvable and not long-term.

**6.4 THE INTERNAL CONSISTENCY OF THE DRS-R-98:** Item analysis was conducted. Missing items for each variable of the DR-R-98 were analysed. 4% of the data for the item 'thought process' were missing. There was 1 missing value for the item 'visuo-spatial problems', but for the remaining 14 items there was none. Therefore there do not appear to be any redundant items in the scale. Cronbach's alpha scores were calculated and it was found that the items were correlated to each other. The diagnostic items and severity items were also analysed separately (table 6) and even used alone the diagnostic items were consistent.

**Table 5 Item Analysis and Internal Consistency:**

DRS on admission		N (%)	Cronbach's alpha
Item	Scores		
Sleep/wake cycle	Not present	0	0.87
	Mild sleep disturbance	1	
	Moderate sleep disturbance	2	
	Severe sleep disturbance	3	
		56 (22)	
		91 (37)	
		89 (36)	
		13 (5)	

	Missing		0 (0)	
Perceptual disturbances	Not present	0	180 (72)	0.87
	Mild perceptual disturbances	1	7 (3)	
	Illusions present	2	1 (0)	
	Hallucinations present	3	61 (25)	
	Missing		0 (0)	
Delusions	Not present	0	147 (59)	0.86
	Mildly suspicious	1	25 (10)	
	Unusual ideation	2	6 (2)	
	Delusional	3	71 (29)	
	Missing		0 (0)	
Lability of affect	Not present	0	177 (72)	0.87
	Affect altered	1	47 (19)	
	Affect inappropriate to situation	2	18 (7)	
	Severe disinhibition of emotions	3	3 (1)	
	Missing		0 (0)	
Language	Normal	0	157 (63)	0.86
	Mild impairment	1	37 (15)	
	Moderate impairment	2	28 (11)	
	Severe impairment	3	27 (11)	
	Missing		0 (0)	
Thought process	Normal processes	0	129 (51)	0.85
	Tangential thought processes	1	47 (19)	
	Associations loosely connected occasionally	2	36 (14)	
	Associations loosely connected most of the time	3	26 (10)	
	Missing		11 (4)	
Motor agitation	No restlessness	0	178 (71)	0.86
	Mild restlessness	1	40 (16)	
	Moderately motor agitation	2	28 (11)	
	Severe motor agitation	3	3 (1)	
	Missing		0 (0)	
Motor retardation	No slowness in movements	0	135 (54)	0.86
	Mildly reduced frequency of movements	1	49 (20)	
	Moderately motor retardation	2	49 (20)	
	Severe motor retardation	3	16 (6)	
	Missing		0 (0)	
Orientation	Orientated	0	48 (19)	0.86
	Disorientated to either time or place	1	71 (29)	
	Disorientated to time and place	2	112 (45)	

	Disorientated to person	3	18 (7)	
	Missing		0 (0)	
Attention	Alert	0	96 (39)	0.85
	Mildly distractible	1	65 (26)	
	Moderate inattention	2	50 (20)	
	Severe difficulty in focusing/sustaining attention	3	38 (15)	
	Missing		0 (0)	
Short term memory	Short term memory intact	0	38 (15)	0.86
	Recalls 2/3 items	1	34 (14)	
	Recalls 1/3 items	2	37 (15)	
	Recalls 0/3 items	3	140 (56)	
	Missing		0 (0)	
Long term memory	Long-term memory intact	0	82 (33)	0.86
	Recalls 2/3 items	1	42 (17)	
	Recalls 1/3 items	2	47 (19)	
	Recalls 0/3 items	3	78 (31)	
	Missing		0 (0)	
Visuospatial ability	No impairment	0	75 (30)	0.85
	Mild impairment	1	62 (25)	
	Moderate impairment	2	56 (22)	
	Severe impairment	3	55 (22)	
	Missing		1 (0)	
Temporal onset of symptoms	No change from usual behaviour	0	155 (62)	0.87
	Onset of symptoms over weeks to a month	1	33 (13)	
	Acute change over days to a week	2	28 (11)	
	Abrupt change over hours to a day	3	33 (13)	
	Missing		0 (0)	
Fluctuation of symptom severity	No fluctuation	0	182 (73)	0.87
	Fluctuation over hours	1	42 (17)	
	Fluctuation over minutes	2	24 (10)	
	Missing		1 (0)	
Physical presence	None present	0	58 (23)	0.87
	Presence of any physical disorder	1	61 (25)	
	Drug/medical problem altering behaviour	2	130 (52)	
	Missing		0 (0)	

**Table 6 Internal Consistency of diagnostic items, severity items and total:**

Items	Cronbach's alpha
Diagnostic items only	0.66
Severity scale only	0.88
Total scale	0.87

This indicates that despite the apparent heterogeneity of the different items the scale measures a single unidimensional concept.

### **6.5 THE SENSITIVITY AND SPECIFICITY OF THE DRS-R-98:**

The sensitivity and specificity of the DRS-R-98 were calculated. Psychiatric and clinical reports were used to provide a 'gold standard' for the identification of mental health problems in a sub-sample of the population. 20 cases were diagnosed clinically with delirium. By using the cut-off of 17.75 (as recommended by the scale's author) participants who scored as positive or negative for delirium were compared with the psychiatric and medical diagnoses. The positive predictive value and negative predictive values were also calculated.

**Table 7: Sensitivity and Specificity:**

	Gold standard: Clinical evaluation by psychiatrist and geriatrician		Total
	Diagnosis of delirium	No diagnosis of delirium	
DRS-R-98 score >17.75	a) True positive 15	b) False positive 21	36
DRS-R-98 score <17.75	c) False negative 5	d) True negative 52	57
Total	20	73	93

Sensitivity is  $a / (a+c) = 75\%$  (95%CI = 56% - 93%)

Specificity is  $d / (b+d) = 71\%$  (95%CI = 66% - 76%)

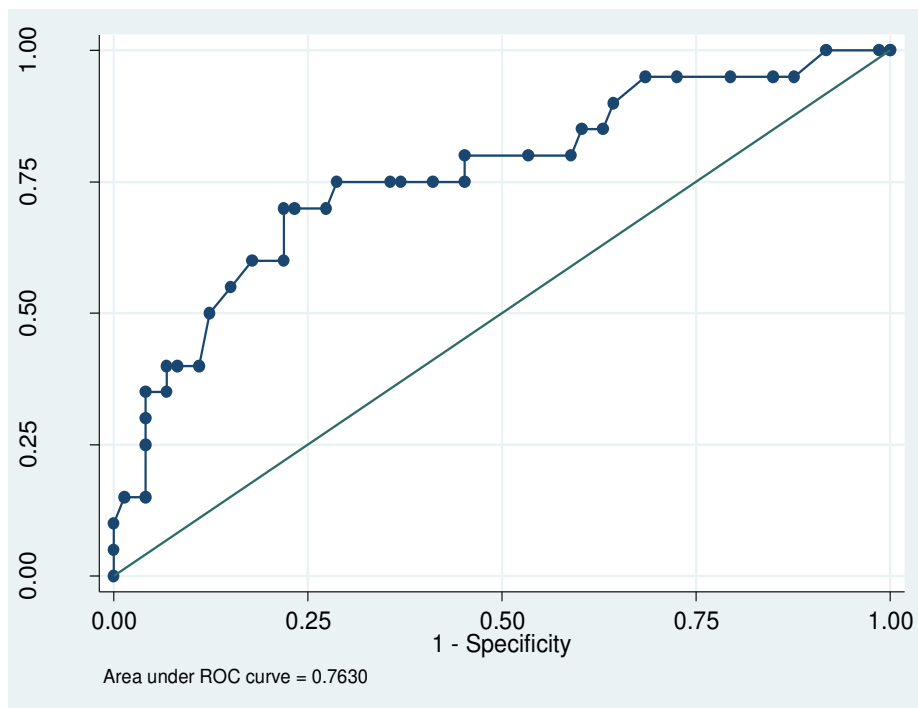
Positive predictive value =  $a/(a+b) = 42\%$  (95%CI = 27% - 57%)

Negative predictive value =  $d/(c+d) = 91\%$  (95%CI = 83% - 98%)

Both sensitivity and specificity were moderate, however as the sample was small and the confidence intervals very wide this may not be precise. The positive and negative predictive values were calculated and showed the proportion of those scoring as positive who were truly positive and those scoring negative who were truly negative. The positive predictive value was low indicating that there is a moderate chance that those scoring positive on the DRS-R-98 did not have delirium.

**6.5.1 ROC Analysis:** ROC analysis using clinical evaluations as a gold standard showed that the DRS-R-98 was able to differentiate delirium or no delirium.

**Figure 5: ROC curve of the DRS-R-98**



From this the DRS-R-98 demonstrated a moderate ability to differentiate delirium from no delirium. The area under the curve is 0.76 (95% CI of 0.63 – 0.88).

Cut-off points for the DRS-R-98 were examined in order to identify which allowed the greatest sensitivity and specificity:



**Table 8 Analysis of DRS-R-98 cut-offs:**

Cut-off point	Sensitivity	Specificity	Correctly classified
≥10	85%	37%	47%
≥11	85%	40%	49%
≥12	80%	41%	49%
≥13	80%	47%	54%
≥14	80%	55%	60%
≥15	75%	55%	59%
≥16	75%	59%	62%
≥17	75%	64%	67%
≥18	75%	71%	72%
≥19	70%	73%	72%
≥20	70%	78%	76%
≥21	60%	78%	74%
≥22	60%	82%	77%
≥23	55%	85%	78%
≥24	50%	88%	80%
≥25	40%	89%	78%

From the ROC analysis the cut-off point which seemed to allow the highest sensitivity and specificity was 18, which was similar to the recommended cut-off of 17.75 (Trzepacz et al. 2001).

#### **6.5.2 Sensitivity and specificity analysis of the DRS-R-98 as determined by recoverable cognitive function:**

Delirium distinguishes itself from dementia and long-term cognitive impairments as it should possible for cognitive function to be recovered after the delirium has been resolved. Changes of 3 or more in MMSE scores (based on previous work by Inouye et al. 2006), from the baseline to 180 day outcome, were analysed and used to further assess the sensitivity and specificity of the DRS-R-98.

**Table 9: Sensitivity and Specificity as determined by recoverable cognitive function:**

	Gold standard: Recovery of cognitive function from baseline to outcome		
	MMSE increased by $\geq 3$	MMSE did not increase	Total
DRS-R-98 score >17.75	a) True positive 20	b) False positive 27	47
DRS-R-98 score <17.75	c) False negative 20	d) True negative 54	74
Total	40	81	121

Sensitivity is  $a / (a+c) = 50\%$  (95%CI = 28% - 72%)

Specificity is  $d / (b+d) = 67\%$  (95%CI = 46% - 88%)

Positive predictive value =  $a / (a+b) = 42\%$  (95%CI = 27% - 57%)

Negative predictive value =  $d / (c+d) = 73\%$  (95%CI = 54% - 92%)

Both sensitivity and specificity were found to be moderate. From this analysis it appeared that 50% of the population who suffered from delirium may not have scored as positive on the DRS-R-98, and 33% of the population were reported as having delirium when they did not. However the confidence intervals were very wide meaning that this may not be conclusive. The positive and negative predictive values were calculated and showed the proportion of those scoring as positive who were truly positive and those scoring negative who were truly negative. The positive predictive value was low indicating that there is a modest chance that those scoring positive on the DRS-R-98 may not have had delirium.

**6.6 DATA AS DEFINED BY DRS-R-98 QUANTILES:** The baseline and outcomes data were split according to quartiles of the DRS-R-98. The associations were recorded and allowed for trends between the quartiles to be analysed.

**6.6.1 Baseline data as defined by DRS-R-98 quartiles:** As shown in table 10, with each increase of DRS-R-98 quartile there was an increase in the odds of the participant being older, having been admitted to hospital from a nursing or residential home and

being more functionally disabled on index admission. There was an increase in the odds ratios showing that participants with higher DRS-R-98 scores are more likely to suffer from dementia and cognitive impairment. Table 10 also shows that with each increase in DRS-R-98 quartile there is an increase in the odds of a participant experiencing neuro-psychiatric behaviours, with the exception of difficulties in sleeping and eating, and elation.

**Table 10: Baseline characteristics as defined by DRS-R-98 quartiles:**

		DRS-R-98 Quartiles				P value
		Q1 Scores 1-7 (Lowest)	Q2 Scores 8-15	Q3 Scores 16-23	Q4 Scores 24-39 (Highest)	
Age (Median, IQR) (n=249)		82 (77-86)	84 (79-88)	85 (80-88)	88 (81-93)	P<0.001 (Sp)
Female (%) (OR) (n=249)		66.1 (1)	65.2 (1.02 CI=0.48-2.15)	67.2 (0.97 CI=0.46-2.05)	66.3 (0.97 CI=0.46-2.05)	P=0.96
Accommodation (%) (n=249)	Own home alone	40	29	20	12	P<0.001
	Own home with relative/carer	20	32	30	18	
	Nursing home	0	20	7	73	
	Residential home	0	8	28	64	
	Mixed home	0	25	8	67	
Admission Barthel Index (%) (n=249)	0-5	8	17	26	50	P<0.005
	6-10	24	24	26	26	
	11-15	19	44	24	13	
	16-20	63	20	12	5	
Prior Barthel Index (%) (n=244)	0-5	0	36	7	57	P=0.08
	6-10	0	24	36	39	
	11-15	17	21	28	35	
	16-20	37	29	20	14	
Decrease in Barthel from Prior to Index (%) (OR) (total=244)	Yes	55 (1)	49 (1.76 CI=0.63-4.9)	58 (0.54 CI=0.15-1.95)	52 (1.20 CI=0.40-3.56)	P=0.23
Charlson Co morbidity (%) (n=249)	0-1	26	28	25	21	P=0.4

	2-3	18	28	23	31	
	4+	33	25	20	28	
SOF frailty (%) (n=248)	0 or 1	23	28	23	26	P=0.9
	2	28	30	22	20	
	3	19	19	26	36	
Medications (n=241)	1 to 5	23	25	24	29	P=0.2
	6 or 7	16	34	31	19	
	8 or 9	21	29	19	31	
	10 +	47	20	20	14	
MEWS (%) (n=249)	0 or 1	25	25	28	22	P=0.8
	2	16	40	9	35	
	3 or more	33	21	18	28	
Dementia (%) (OR) (n=249)	Yes	8 (12.90) (1)	16 (26.23) (1.14 CI=6.12)	31 (49.21) (6.53 CI=2.6- 15.9)	51 (80.95) (28.68 CI=10.84 - 75.90)	P<0.0001
MMSE (%) (n=248)	0-9	0	8	24	69	P<0.0001
	10-20	9	35	38	19	
	21-24	51	36	13	0	
	≥25	71	26	2	0	
CSDDD (>10) (%) (n=249)	Mild Depression (CSDDD 11-18)	23	23	27	26	P=0.003
	Major Depression (CSDDD ≥19)	9	21	18	52	
CSDDD –Any depression	N (%) (OR)	26 (41.94) (1)	27 (44.26) (1.09 CI=0.53- 2.24)	36 (57.14) (1.84 CI=0.90- 3.75)	43 (68.25) (2.97 CI=1.43 - 6.18)	(P=0.009)
NPI (moderate to marked) (%) (n=249)	Delusions	0	10	48	42	P<0.001
	Hallucinations	0	32	24	44	P=0.01
	Agitation and aggression	0	3	34	63	P<0.001
	Depression	22	18	26	34	P=0.04
	Anxiety	26	17	21	37	P=0.01
	Elation	0	0	33	67	P=0.3
	Apathy	10	22	22	47	P<0.001
	Disinhibition	0	5	32	63	P<0.001
	Irritability	14	16	36	34	P=0.02
	Psychomotor activity	5	14	24	57	P<0.001
	Sleep problems	25	22	19	34	P=0.1

	Appetite or eating problems	21	24	23	32	P=0.2
NPI total	Median (IQR)	17 (10-25)	21 (12-28)	25 (19-40)	38 (27-62)	P<0.001

**6.6.2 Outcomes data as defined by DRS-R-98 quartiles:** As shown in table 11, with each increase in DRS-R-98 quartile there was an increase in the odds of the participant being functionally disabled at outcome (as measured by the Barthel Index), though the change in functional status from admission to outcome was not significant. DRS-R-98 scores were significantly associated with recoverable cognitive impairment (an increase in MMSE score of 3 or more) indicating that the DRS-R-98 was measuring more acute cognitive impairments.

There was no significant association between mortality, hospital readmissions or length of stay and DRS-R-98 quartile. There were also no associations between DRS-R-98 quartile and quality of life at outcome.

**Table 11: 180 day outcome data as defined by DRS-R-98 quartiles**

		DRS-R-98 Quartiles				P value
		Q1 Scores 1-7 (Lowest)	Q2 Scores 8-14	Q3 Scores 15-23	Q4 Scores 24-39 (Highest)	
Mortality at 6 months (n=249) (%) (OR)	Dead	45 (21.79) (OR=1)	16 (20.51) (OR =0.96 CI= 0.43 – 2.14)	18 (23.1) (OR=1.08 CI=0.49- 2.36)	27 (34.62) (OR=1.98 CI=0.93- 4.1)	P=0.17
Length of stay in hospital	Mean (days)	23	29	25	21	P=0.46
Length of stay during index admission	Mean (days)	14	17	16	15	P=0.9
Hospital re-admissions	Mean (days)	8	12	9	7	P=0.38
Moved to Care Home (n=247) (OR)	Yes (%)	11 (23.9) 1	10 (21.7) (0.92 CI=0.36- 2.37)	14 (30.43) (1.35 CI=0.55- 3.26)	11 (23.9) (0.98 CI=0.39- 2.46)	P=0.8
Outcome Barthel Index (n=141)	0-5	5	31	26	39	P<0.001
	6-10	10	17	41	31	
	11-15	30	27	30	12	
	16-20	48	35	15	3	

Decrease in Barthel from Index to Outcome (n) (OR) (n=141)	Yes	10 (1)	14 (0.71 CI=0.26-1.9)	14 (0.77 CI=0.28-2.06)	13 (0.51 CI=0.18-1.44)	P=0.65
Decrease Barthel Index of 3+ (n)(OR) (n=141)	Yes	3 (1)	9 (0.31 CI=0.76 -1.26)	9 (0.33 CI=0.82-1.34)	9 (0.21 CI=0.05-0.89)	P=0.16
Increase Barthel Index to Outcome (n) (OR) (n=141)	Yes	20 (1)	21 (0.77 CI=0.31-1.95)	19 (0.7 CI=0.31-1.94)	13 (0.57 CI=0.21-1.55)	P=0.23
Increase in Barthel from Index of 3+ (n) (OR) (n=141)	Yes	12 (1)	14 (0.99 CI=0.37-2.57)	11 (0.75 CI=0.27-2.01)	8 (0.7 CI=0.23-2.04)	P=0.86
DEMQoL	Median (IQR)	81	84	84	81	P=0.83
EQ5D	Median (IQR)	0.46	0.32	0.30	0.23	P=0.06
Outcome MMSE (%) (n=121)	0-9	0	19	36	45	P<0.001
	10-20	16	38	24	22	
	21-24	29	35	29	6	
	≥25	53	25	19	3	
Increase of MMSE by 3+ (%) (n=121) (OR)	Yes	4 (10.0) (1)	9 (23) (2.4 CI=0.66-8.96)	17 (43) (6.5 CI=1.86-22.6)	10 (25) (4.64 CI=1.22-17.53)	P=0.01
Outcome NPI (%)	Delusions (n=15)	7	13	40	40	P=0.3
	Hallucinations (n=8)	0	0	50	50	P=0.07
	Agitation and aggression (n=19)	5	26	42	26	P=0.4
	Depression (n=17)	6	18	47	29	P=0.3
	Anxiety (n=21)	14	14	52	19	P=0.1
	Elation (n=2)	0	0	100	0	P=0.2
	Apathy (n=37)	8	27	35	30	P=0.4
	Disinhibition (n=5)	20	20	20	40	P=0.8
	Irritability (n=14)	0	21	50	29	P=0.2
	Psychomotor activity (n=13)	0	8	46	46	P=0.04
	Sleep problems (n=19)	11	16	42	32	P=0.4
	Appetite or eating problems (n=27)	26	30	22	22	P=0.3
NPI total	Median (IQR)	15 (4-19)	8 (3-25)	12 (8-30)	14 (5-29)	P=0.17

## **7 DISCUSSION**

**7.1 MAIN FINDINGS:** From the initial analysis there was high prevalence of mental health problems in older people on general hospital wards. 250 participants were recruited into the MCOP-BMH cohort population, of varying functional ability and suffering from a variety of physical and mental health problems. The predominant mental health problems were mild depression, cognitive impairment and delirium. Previous research indicates that delirium is unrecognised in general hospitals (Schofield 2008). In this study it was found that out of the 249 patients recruited on general hospital wards, 43% had delirium according to the DRS-R-98, of whom 67% also had a diagnosis of dementia. At the 180 day outcome 31% of participants died, 19% had moved to a care home after their hospital admission and 22% had decrease in functional ability (a decrease in Barthel score of 3 or more).

**7.1.2 DRS-R-98 SCORES:** The participants scoring within the highest quartile of the DRS-R-98 were more likely to be care home residents, experience long-term disability and have dementia. They were older, and be more likely to suffer from depression and behavioural problems. At 180 day outcome, scores within the highest quartile of the DRS-R-98 appeared to be associated with functional disability (though change in Barthel score from index admission was not significant).

An increase in the MMSE scores at outcome was noted, the odds of which increase in the higher quartiles of the DRS-R-98 scores (with the exception of the highest quartile). Neuro-psychiatric symptoms at baseline, as measured by the NPI, were higher in the patients with higher DRS-R-98 scores. This association was not present at outcome suggesting that neuro-psychiatric problems may have resolved by 180 days in patients suffering from delirium.

However, further analysis shows that the ability of the DRS-R-98 to distinguish delirium from other mental health problems is only modest.

**7.1.3 VALIDITY OF THE DRS-R-98:** Based on the analysis using a gold standard, the DRS-R-98 appears to be moderately accurate as a diagnostic tool with reasonable

sensitivity and specificity when the cut-off of 17.75 was used; however the sample was small so this may not be conclusive. When calculating the sensitivity and specificity based on recovery of cognitive function the DRS-R-98 was shown to have modest validity and to be less accurate when distinguishing those with or without the syndrome.

The face and content validity have been supported through the item analysis. There was also evidence of concurrent validity through the associations between the DRS-R-98 and the MMSE, Barthel and NPI. However, whilst there were associations between some of the neuro-psychiatric inventory items and delirium, for example 'hallucinations', there was no relationship with 'difficulties sleeping'. As research supports this being both a risk factor and symptom of delirium (Sanders and Maze 2010) this does not support the validity of the DRS-R-98.

Some unexpected findings arose from the data analysis as delirium (as identified by the DRS-R-98) was not associated with death, nor was it associated with the number of medications patients were taking on admission or severity of acute illness (as measured by the Modified Early Warning Score). These results could also indicate a lack of validity of the DRS-R-98 as previous studies have shown direct causal relationships (Fong et al. 2009) (Inouye 2000) (Attard et al. 2008).

## **7.2 STRENGTHS:**

**7.2.1 Sample size at baseline:** 250 older patients with mental health problems were recruited and 249 retained. From these participants, data was collected using a battery of scales measuring mental health and functional problems. This large sample allowed a greater amount of data to be collected from patients from varying backgrounds, with varying degrees of disability and cognitive status. This could allow the data to be seen as generalisable to older patient populations in hospital suffering from mental health problems.

**7.2.2 Systematic identification and screening:** This ensured that patients were approached without bias, on a range of hospital wards meaning that data could be



collected from patients with different medical conditions, therefore also supporting the generalisability of the data to older patient on general hospital wards, as opposed to specialist wards.

**7.2.3 Consultee agreement:** This was sought for patients who lacked capacity to consent for themselves to participate in the study. This allowed the collection of data from patients suffering from a range of severities of cognitive impairment.

**7.2.4 Informants:** Carers of the patient participants were approached and in cases where participants were unable to provide information they acted as informants, providing information regarding the patient's usual cognitive ability, functional ability and mental health status during the patient's admission.

**7.2.5 Use of patient's medical records:** These were used to provide a full history regarding the patient's co-morbidities. This allowed an account of the patient's pre-existing and concurrent medical problems to be recorded, as well as the patient's health status on admission.

**7.2.6 Nursing notes and nursing staff:** Information from both staff and notes allowed for the collection of data on patient's functional ability during admission and also if any psychiatric problems were noted. During screening these proved helpful in judging the suitability of potential patient participants.

### **7.3 WEAKNESSES:**

**7.3.1 Screening at 2-5 days of the admission:** As patient participants were approached at days 2 to 5 of their hospital admission, there was the possibility that if they had been suffering from a mental health problem such as delirium, the condition may have resolved by the time of screening. If this was the case and no evidence of mental health problems was recorded by staff members on the wards the patient may have been screened as not suitable for recruitment. This could mean that data would not have been collected from patients for whom the mental health problem resolved.

**7.3.2 No consultee:** In cases where the participants lacked the capacity to consent to their participation, attempts to contact family members or a significant next of kin were made. However, in some cases, no such person was available. This meant that patients in these circumstances could not be recruited, and the differences between groups with an involved next of kin and those without could not be explored. It must also be noted that the researchers were confined to normal working hours (9am to 6pm). This meant that the differences between patients who had family members who were able to visit between these hours, and patients whose family members could not, was not explored.

**7.3.3 Missing values:** At the 180 day follow-up, over half of the 249 participants were unavailable for outcome data collection. Due to the high mortality rate of the population (almost a third died), participants moving home or changing telephone numbers rendering them unreachable, and carers of the participants consenting only to answering questions over the telephone meant that full data collection was not possible. Data analysis of outcomes data used a smaller amount of participants' data and lacked some of the power the baseline data may have had.

**7.3.4 Bias:** Participants were aware of the nature of the MCOP-BMH cohort study. This may have caused patients and informants to feel obliged to over-report any symptoms or experiences of mental health problems that they had. On recruitment, the nature of the study may have contributed to potential participants declining to take part, due to the perceived stigma of having a mental health problem.

**7.3.5 Dates of clinical and psychiatric assessment:** The structured assessments performed by the geriatrician assessors and psychiatrists were sometimes conducted up to ten days after the DRS-R-98 was used. This could mean that the delirium resolved by the time the assessment took place and unless evidence had been recorded by ward staff it would not have been detected.

## **7.4 DELIRIUM IN A GENERAL HOSPITAL:**

**7.4.1 Delirium is common:** As the DRS-R-98 has moderate sensitivity and specificity when distinguishing delirium from other mental health problems; it can be used to estimate the proportion of patients with delirium, dementia or both. Using the DRS-R-98 cut-off of 17.75 delirium was common in older patients with mental health problems in general hospitals, as 43% of the cohort population scored positive for delirium. Due to the screening methods, and the sample of wards from which the participants were recruited, the cohort population appears to be representative of a wider hospital population (Goldberg et al. 2012). From this we can estimate that for all patients over 70 on general hospital wards, 28% had delirium and 19% had both delirium and dementia.

Delirium can cause distressing symptoms. According to the DRS-R-98 25% of the population suffered from hallucinations, 29% from delusions and 11% from language difficulties. Being frightened by visions and persecutory thoughts, without the ability to communicate or ask for help could be very frightening for patients in hospital. Also, as 13% of patients scored highest for temporal onset (meaning that the patients' symptoms occurred within hours to a day) this alteration in normal abilities and sudden cognitive difficulties could also be very distressing to both patients and those who know them.

**7.4.2 Using the DRS-R-98:** The DRS-R-98 appears to have both moderate sensitivity and specificity. However, false positive and false negative diagnoses were made. This implies that even when using a tool specifically designed to identify delirium, cases may still be missed and misdiagnoses of delirium may be made in patients suffering from other mental health problems.

**7.4.3 Poor prognosis:** There were no significant associations between mortality, length of stay or decrease in functional ability. Patients with higher DRS-R-98 scores were more functionally disabled at both admission and outcome, but as there was no

relationship between changes in Barthel index and DRS-R-98 scores delirium did not appear to exacerbate this.

**7.4.4 Recoverability:** As there is a significant association between an increase in cognitive ability and DRS-R-98 score, this indicates that cognitive impairment caused by delirium is recoverable. However, as the mortality rate and number of withdrawals were high, there was inadequate power to support this. Also, as initial questionnaires were carried out on general hospital wards and outcome questionnaires usually in the patients' homes there are environmental issues which may have led to an increase in recovery of cognition. Firstly, patients were in hospital because they were ill, which could affect concentration. Secondly, hospital wards are often noisy, busy places and patients could be better orientated and relaxed in their own homes.

There was no relationship between delirium and recovery of functional ability, which would occur if delirium was resolvable. This could be due to poor identification by ward staff, a failure in rehabilitation, complications (such as falls or pressure sores), over-sedation, deconditioning or immobility.

## **7.5 CONCLUSION:**

Results from this thesis show that in this population there was a high prevalence of delirium and dementia, and a significant association between the two was found. As both affect patients' cognitive function this means that delirium is not easy to identify in patients already suffering from dementia related impairment. The DRS-R-98 has moderate levels of sensitivity and specificity in detecting delirium in a population all screened positive for mental health problems. The levels of sensitivity and specificity are lower than previously reported; this thesis shows the sensitivity and specificity to be 75% and 71% respectively, when compared to clinical diagnosis. These findings are not dissimilar those of Andrew et al. 2009, who reported that when using the DRS-R-98 to distinguish delirium from dementia, the sensitivity and specificity of the scale were reduced. If the DRS-R-98 were to be used for detecting delirium in older patients

suffering from mental health problems on general hospital wards, delirium could be missed in 25% of patients and misdiagnosed in 29%. Therefore, in this context and population the DRS-R-98 does not perform sufficiently validly and if diagnoses are made using it they should be confirmed by clinical or mental state examinations. However, the DRS-R-98 appears to be sufficiently valid to be used in epidemiological studies, where non differential misclassification causes a loss of power, rather than directly affecting a patient's care.

### **7.8 IMPLICATIONS FOR FURTHER RESEARCH:**

If the validity of the DRS-R-98 is to be assessed the study should be replicated, using a greater sample and including patients with prior diagnoses of mental health problems and a control group. To fully assess the scale's criterion validity a psychiatric assessment should be performed for a larger sample of the study population (if not all) and a full clinical interview should take place at the same time that the DRS-R-98 is used. It may also be prudent to collect outcomes data at 90 days as well as 180 days, as mortality at 180 days was high.

From this thesis it is also evident that new and better ways of diagnosing and measuring delirium in people with dementia are needed.

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## Appendix 1: DRS-R-98 (Trzepacz et al. 2001)

### DELIRIUM RATING SCALE-R-98 (DRS-R-98)

This is a revision of the Delirium Rating Scale (Trzepacz et al. 1988). It is used for initial assessment and repeated measurements of delirium symptom severity. The sum of the 13 item scores provides a severity score. All available sources of information are used to rate the items (nurses, family, chart) in addition to examination of the patient. For serial repeated ratings of delirium severity, reasonable time frames should be chosen between ratings to document meaningful changes because delirium symptom severity can fluctuate without interventions.

### DRS-R-98 SEVERITY SCALE

#### 1. Sleep-wake cycle disturbance

Rate sleep-wake pattern using all sources of information, including from family, caregivers, nurses' reports, and patient. Try to distinguish sleep from resting with eyes closed.

0. Not present
1. Mild sleep continuity disturbance at night or occasional drowsiness during the day
2. Moderate disorganization of sleep-wake cycle (e.g., falling asleep during conversations, napping during the day or several brief awakenings during the night with confusion/behavioral changes or very little nighttime sleep)
3. Severe disruption of sleep-wake cycle (e.g., day-night reversal of sleep-wake cycle or severe circadian fragmentation with multiple periods of sleep and wakefulness or severe sleeplessness.)

#### 2. Perceptual disturbances and hallucinations

Illusions and hallucinations can be of any sensory modality. Misperceptions are "simple" if they are uncomplicated, such as a sound, noise, color, spot, or flashes and "complex" if they are multidimensional, such as voices, music, people, animals, or scenes. Rate if reported by patient or caregiver, or inferred by observation.

0. Not present
1. Mild perceptual disturbances (e.g., feelings of derealization or depersonalization; or patient may not be able to discriminate dreams from reality)
2. Illusions present
3. Hallucinations present

#### 3. Delusions

Delusions can be of any type, but are most often persecutory. Rate if reported by patient, family or caregiver. Rate as delusional if ideas are unlikely to be true yet are believed by the patient who cannot be dissuaded by logic. Delusional ideas cannot be explained otherwise by the patient's usual cultural or religious background.

0. Not present
1. Mildly suspicious, hypervigilant, or preoccupied
2. Unusual or overvalued ideation that does not reach delusional proportions or could be plausible
3. Delusional

#### 4. Lability of affect

Rate the patient's affect as the outward presentation of emotions and not as a description of what the patient feels.

0. Not present
1. Affect somewhat altered or incongruent to situation; changes over the course of hours; emotions are mostly under self-control
2. Affect is often inappropriate to the situation and intermittently changes over the course of minutes; emotions are not consistently under self-control, though they respond to redirection by others
3. Severe and consistent disinhibition of emotions; affect changes rapidly, is inappropriate to context, and does not respond to redirection by others

#### 5. Language

Rate abnormalities of spoken, written or sign language that cannot be otherwise attributed to dialect or stuttering. Assess fluency, grammar, comprehension, semantic content and naming. Test comprehension and naming nonverbally if necessary by having patient follow commands or point.

0. Normal language
1. Mild impairment including word-finding difficulty or problems with naming or fluency
2. Moderate impairment including comprehension difficulties or deficits in meaningful communication (semantic content)
3. Severe impairment including nonsensical semantic content, word salad, muteness, or severely reduced comprehension

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## DELIRIUM RATING SCALE-REVISED-98

### 6. Thought process abnormalities

Rate abnormalities of thinking processes based on verbal or written output. If a patient does not speak or write, do not rate this item.

0. Normal thought processes
1. Tangential or circumstantial
2. Associations loosely connected occasionally, but largely comprehensible
3. Associations loosely connected most of the time

### 7. Motor agitation

Rate by observation, including from other sources of observation such as by visitors, family and clinical staff. Do not include dyskinesia, tics, or chorea.

0. No restlessness or agitation
1. Mild restlessness of gross motor movements or mild fidgetiness
2. Moderate motor agitation including dramatic movements of the extremities, pacing, fidgeting, removing intravenous lines, etc.
3. Severe motor agitation, such as combativeness or a need for restraints or seclusion

### 8. Motor retardation

Rate movements by direct observation or from other sources of observation such as family, visitors, or clinical staff. Do not rate components of retardation that are caused by parkinsonian symptoms. Do not rate drowsiness or sleep.

0. No slowness of voluntary movements
1. Mildly reduced frequency, spontaneity or speed of motor movements, to the degree that may interfere somewhat with the assessment.
2. Moderately reduced frequency, spontaneity or speed of motor movements to the degree that it interferes with participation in activities or self-care
3. Severe motor retardation with few spontaneous movements.

### 9. Orientation

Patients who cannot speak can be given a visual or auditory presentation of multiple choice answers. Allow patient to be wrong by up to 7 days instead of 2 days for patients hospitalized more than 3 weeks. Disorientation to person means not recognizing familiar persons and may be intact even if the person has naming difficulty but recognizes the person. Disorientation to person is most severe when one doesn't know one's own identity and is rare. Disorientation to person usually occurs after disorientation to time and/or place.

0. Oriented to person, place and time
1. Disoriented to time (e.g., by more than 2 days or wrong month or wrong year) or to place (e.g., name of building, city, state), but not both
2. Disoriented to time and place
3. Disoriented to person

### 10. Attention

Patients with sensory deficits or who are intubated or whose hand movements are constrained should be tested using an alternate modality besides writing. Attention can be assessed during the interview (e.g., verbal perseverations, distractibility, and difficulty with set shifting) and/or through use of specific tests, e.g., digit span.

0. Alert and attentive
1. Mildly distractible or mild difficulty sustaining attention, but able to refocus with cueing. On formal testing makes only minor errors and is not significantly slow in responses
2. Moderate inattention with difficulty focusing and sustaining attention. On formal testing, makes numerous errors and either requires prodding to focus or finish the task
3. Severe difficulty focusing and/or sustaining attention, with many incorrect or incomplete responses or inability to follow instructions. Distractible by other noises or events in the environment

### 11. Short-term memory

Defined as recall of information (e.g., 3 items presented either verbally or visually) after a delay of about 2 to 3 minutes. When formally tested, information must be registered adequately before recall is tested. The number of trials to register as well as effect of cueing can be noted on scoresheet. Patient should not be allowed to rehearse during the delay period and should be distracted during that time. Patient may speak or nonverbally communicate to the examiner the identity of the correct items. Short-term deficits noticed during the course of the interview can be used also.

0. Short-term memory intact
1. Recalls 2/3 items; may be able to recall third item after category cueing
2. Recalls 1/3 items; may be able to recall other items after category cueing
3. Recalls 0/3 items

## 12. Long-term memory

Can be assessed formally or through interviewing for recall of past personal (e.g., past medical history or information or experiences that can be corroborated from another source) or general information that is culturally relevant. When formally tested, use a verbal and/or visual modality for 3 items that are adequately registered and recalled after at least 5 minutes. The patient should not be allowed to rehearse during the delay period during formal testing. Make allowances for patients with less than 8 years of education or who are mentally retarded regarding general information questions. Rating of the severity of deficits may involve a judgment about all the ways long-term memory is assessed, including recent and/or remote long-term memory ability informally tested during the interview as well as any formal testing of recent long-term memory using 3 items.

0. No significant long-term memory deficits
1. Recalls 2/3 items and/or has minor difficulty recalling details of other long-term information
2. Recalls 1/3 items and/or has moderate difficulty recalling other long-term information
3. Recalls 0/3 items and/or has severe difficulty recalling other long-term information

## 13. Visuospatial ability

Assess informally and formally. Consider patient's difficulty navigating one's way around living areas or environment (e.g., getting lost). Test formally by drawing or copying a design, by arranging puzzle pieces, or by drawing a map and identifying major cities, etc. Take into account any visual impairments that may affect performance.

0. No impairment
1. Mild impairment such that overall design and most details or pieces are correct; and/or little difficulty navigating in his/her surroundings
2. Moderate impairment with distorted appreciation of overall design and/or several errors of details or pieces; and/or needing repeated redirection to keep from getting lost in a newer environment despite, trouble locating familiar objects in immediate environment
3. Severe impairment on formal testing; and/or repeated wandering or getting lost in environment

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### DRS-R-98 OPTIONAL DIAGNOSTIC ITEMS

These three items can be used to assist in the differentiation of delirium from other disorders for diagnostic and research purposes. They are added to the severity score for the total scale score, but are NOT included in the severity score.

## 14. Temporal onset of symptoms

Rate the acuteness of onset of the initial symptoms of the disorder or episode being currently assessed, not their total duration. Distinguish the onset of symptoms attributable to delirium when it occurs concurrently with a different preexisting psychiatric disorder. For example, if a patient with major depression is rated during a delirium episode due to an overdose, then rate the onset of the delirium symptoms.

0. No significant change from usual or longstanding baseline behavior
1. Gradual onset of symptoms, occurring over a period of several weeks to a month
2. Acute change in behavior or personality occurring over days to a week
3. Abrupt change in behavior occurring over a period of several hours to a day

## 15. Fluctuation of symptom severity

Rate the waxing and waning of an individual or cluster of symptom(s) over the time frame being rated. Usually applies to cognition, affect, intensity of hallucinations, thought disorder, language disturbance. Take into consideration that perceptual disturbances usually occur intermittently, but might cluster in period of greater intensity when other symptoms fluctuate in severity.

0. No symptom fluctuation
1. Symptom intensity fluctuates in severity over hours
2. Symptom intensity fluctuates in severity over minutes

## 16. Physical disorder

Rate the degree to which a physiological, medical or pharmacological problem can be specifically attributed to have caused the symptoms being assessed. Many patients have such problems but they may or may not have causal relationship to the symptoms being rated.

0. None present or active
1. Presence of any physical disorder that might affect mental state
2. Drug, infection, metabolic disorder, CNS lesion or other medical problem that specifically can be implicated in causing the altered behavior or mental state

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## Appendix 2: Summary data from literature search

Study	Setting	Population	Method	DSM IV Criteria	Gold standard.	Validity
Delirium subtype identification and the validation of the Delirium Rating Scale—Revised-98 (Dutch version) in hospitalised elderly patients. deRoos et al. (2006)	General hospital	Inpatients 65 years and over. First cohort: 65 patients; consisted of 23 patients with delirium, 22 patients with dementia, and 20 non-psychiatric comparison patients.	First: validation and reliability study of the Dutch version of the DRS-R-98.	Yes	Yes	Face validity and content validity (appears to measure delirium). IRR (0.97). Concurrent validity with MMSE. Internal consistency ( $\alpha=0.94$ and if one item was deleted $\alpha=0.94-0.95$ ). Criterion validity (compared with psychiatric diagnosis using DSM IV, scores DRS-R-98 -D significantly higher in delirium group.
Delirium subtype identification and the validation of the Delirium Rating Scale—Revised-98 (Dutch version) in hospitalised elderly patients. deRoos et al. (2006)	General hospital	Inpatients 65 years and over. Second cohort: 54 delirious patients.	Second: Delirium subtype analysis DSM-IV criteria were assessed with the DRS-R-98	Yes	Yes	Concurrent validity with IQCODE (nearly all delirious patients had had a prior cognitive decline). Further, hypoactive and non-hypoactive delirium could be discerned. Non-hypoactive delirium was best predicted by a positive score on the DRS-R-98 items 'affect liability' and/or 'motor agitation', possible predictive validity.
Delirium-O-Meter: a nurses' rating scale for monitoring delirium severity in geriatric patients. deJonghe et al. (2005)	General hospital	92 inpatients, 67 years and over; 56 with delirium, 24 with dementia or other cognitive disturbances (no delirium) and 12 with other psychiatric disorders or no mental disorder.	Analysis of cross sectional and repeated assessments data 48hours after patient's admission to the hospital.	Yes	Yes	DRS-R-98 concurrent validity with DOM. Paper states of the DRS-R-98 'reliability and validity of the DRS has been established' but not further details.
Spanish version of the Delirium Rating Scale-Revised-98: Reliability and validity. Fonseca et al. (2003)	General hospital	30 patients, 73 years and over; 18 women and 9 men, with a mean age of 81 ( $\pm 8$ ) years with a DSM-IV diagnosis of delirium.	Validation and reliability study.	Yes	Yes	IRR = 0.96. Concurrent validity with MMSE, OS and MEC. Internal consistency ( $\alpha=0.78$ . If an item was removed $\alpha=0.73-0.81$ ).

Study	Setting	Population	Method	DSM IV Criteria	Gold standard.	Validity
Japanese Version of the Delirium Rating Scale, Revised-98 (DRS-R98-J): Reliability and Validity. Kato et al. (2010)	General hospital	81 inpatients, 40 years and over, were consecutively referred to the psychiatric consultation service. They were divided into two groups for this study: delirium (N=48) or non-delirium (including dementia) (N=33).	Validation and reliability study.	Yes	Yes	Face validity and content validity (appears to measure delirium). Concurrent validity with MMSE and CGI-S-D. ICC high ( $\alpha = 0.92$ ). If an item was removed $\alpha = 0.90$ and $0.92$ . Discriminant validity: using a cut-off of 14.5 resulted in 98% sensitivity and 94% specificity and comparing delirium and dementia groups: 98% sensitivity and 75% specificity,
Factor Analysis of The Colombian Translation of The Delirium Rating Scale (DRS), Revised-98. Franco et al. (2009)	General hospital	161 adult surgical inpatients (not comatose, in obstetrics or intensive care units) 23 years or over. 32 had delirium (of which 7 also had dementia), and 129 did not have delirium (of which 6 had dementia)(according to DSM-IV-TR criteria).	A factor analysis of the DRS-R-98 (case control).	Yes	Yes	Face validity and content validity (rank means for all individual items significantly higher in delirium groups than non-delirium group). Construct validity.
Validation of the Delirium Rating Scale-Revised-98: Comparison With the Delirium Rating Scale and the Cognitive Test for Delirium. Trzepacz (2001)	Medical, surgical, psychiatric, rehabilitation, and nursing home care inpatient units of Medical Centre.	68 inpatients, 16 years and over. Medical, surgical, psychiatric, rehabilitation, and nursing home care inpatients. 24 delirious, 13 demented, 9 schizophrenic, 12 depressed, and 10 "other."	Validation and reliability study.	Yes	Yes	Face and content validity (appears to measure delirium) on Kruskal-Wallis comparisons $p < 0.001$ . Concurrent validity with DRS and DSM-IV (and ability to measure change). Internal consistency ( $\alpha = 0.90$ ). If an item removed $\alpha = 0.88$ to $0.90$ . ICC = $0.99$ . Using a cut-off of 17.75 sensitivity=92% and specificity = 95%.

Study	Setting	Population	Method	DSM IV Criteria	Gold standard	Validity
Inter-rater reliability of the DRS-R-98 in detecting delirium in frail elderly patients. Andrew et al. (2009)	Geriatric medical ward.	145 participants, aged 75 years and over, recruited as inpatients from geriatric medical wards, or as outpatients from emergency department. 33 no cognitive impairment (NCI), 21 cognitive impairment no dementia (CIND), 36 with dementia, 23 with delirium, 10 delirium and CIND and 22 delirium and dementia.	Case-control.	Yes	Yes	Concurrent validity with MMSE (negatively correlated, $r=-0.70$ ). Good IRR ( $r=0.93$ and I.C.C= 0.92). Moderate inter-rater agreement (0.76). However, sensitivity low between dementia and delirium groups (<0.6)
Chinese version of the Delirium Rating Scale-Revised-98: reliability and validity. Huang et al. (2009)	General hospital and psychiatric centre.	59 patients, 20 years and over, with delirium (n = 28), alcohol dependence (n = 9), dementia (n =11), and schizophrenia and bipolar disorder (n = 11).	Case series.	Yes	Yes	Face and content validity. High IRR (ICC =0.99). High internal consistency $\alpha = 0.86$ . Concurrent validity with MMSE; significant inverse correlation ( $r = -0.63$ , $P > 0.001$ ). With cut-off of 15.5 for total score, sensitivity = 89.3% and specificity = 96.8%.
Portuguese version of the Delirium Rating Scale-Revised-98: reliability and validity. Negreiros et al. (2008)	Clinical, psychiatric, surgical and emergency wards of general hospital.	64 inpatients, 23 years and over, from five diagnostic groups (27 delirium, 11 demented, 11 depressed, 8 schizophrenic and 7 'other').	Case series.	Yes	Yes	Face and content validity (mean and median DRS-R-98 total scores significantly distinguished delirium from the other groups ( $p<0.001$ ) inc. dementia). High inter-rater reliability (ICC between 0.9 and 1) and internal consistency ( $\alpha =0.91$ ). Concurrent validity between DRS-R-98 severity scores and CGI. With a cut-off value of 20 sensitivity = 92.6% and specificity = 94.6%.



<b>Study</b>	<b>Setting</b>	<b>Population</b>	<b>Method</b>	<b>DSM IV Criteria</b>	<b>Gold standard</b>	<b>Validity</b>
Assessing severity of delirium by the Delirium Observation Screening Scale. Scheffer et al. (2010)	General hospital	Part of larger study: 97 patients: 41 admitted with hip fracture, 56 medical patients.	Validation study of DOS (using delirium as identified by DRS-R-98 as 'gold standard').	Yes	No	Criterion validity, concurrent validity with DOS.
A randomized controlled trial of quetiapine versus placebo in the treatment of delirium. Tahir et al. (2010)	Medical, surgical and orthopaedic wards	42 participants recruited after meeting DSM IV criteria for delirium and scoring 15 or higher on DRS-R-98.	Double blind RCT.	Yes	No	Content validity
Risperidone versus olanzapine for the treatment of delirium. Kim et al. (2011)	General hospital	32 subjects (18 male and 14 female), aged 36+ years (median, 70 years). Twenty-three (71.9%) patients had malignant cancer, and nine had femur fracture, head trauma, or pneumonia.	7 - day, rater blind, RCT	At baseline	No	Content validity

**Appendix 3: MCOP-BMH Screening questionnaire**

**Mental Health Problems on Hospital Medical Wards**

Study number \_\_\_\_\_  
 Ward \_\_\_\_\_  
 Researcher \_\_\_\_\_

Date \_\_\_\_\_

1. Can the patient speak enough to communicate? If no, is this due to severe aphasia or tracheostomy? If so, exclude. If not, screen is **positive**.
2. Is the patient unconscious, drowsy or too unwell to answer? If yes, go straight to question 4, or review to day five, and exclude if still unable.

<b>1. Ask: Will you do a short memory test for me?</b>	1= correct, 0= wrong or unable	Positive
What is your age? (exact)		Yes  No
What is the time? (nearest hour)		
Please repeat the address '42 West Street' and try to remember it.		
What is the year? (exact)		
What is the name of this hospital? (any generally accepted)		
Can you tell me these 2 people do? (show photographs)		
What was your date of birth? (month and year correct)		
What was the year of the first world war? (accept 1914 or 1914-18)		
What is the name of the current monarch?		
Please count backwards from 20-1 (all correct)		
Recall the address		
<b>TOTAL: Less than or equal to 7 is positive</b>		

<b>2. May I now ask some questions about your mood?</b>		Positive
Are you basically satisfied with life?	No=1, Yes=0	Yes
Do you feel that your life is empty	No=0, Yes=1	No
Are you afraid that something bad is going to happen to you?	No=0, Yes=1	
Do you feel happy most of the time?	No=1, Yes=0	
<b>TOTAL: One or more is positive</b>		

In the past month:	Yes=1, no=0	Positive
Have you been bothered by nerves, feeling anxious, or being on edge?		Yes
Have you been bothered by worrying about a lot of different things?		No
Had an anxiety or panic attack? (sudden feeling of panic)		
<b>TOTAL: Two or more is positive</b>		

**3. Now I'd like to ask some questions about drinking alcohol.**

<b>Do you ever drink alcohol? If no, screen negative. If yes, ask:</b>	Yes=1, no=0	Positive
Have you ever felt you needed to cut down on your drinking?		Yes
Have people annoyed you by criticising your drinking?		No
Have you ever felt guilty about drinking?		
Have you ever felt you needed a drink first thing in the morning to steady your nerves or to get rid of a hangover (an eye-opener)?		
<b>TOTAL: Two or more is positive</b>		

<b>4. Is there any other reason to suspect that this person might have a mental health problem (e.g. agitated, confused, appearing to hallucinate, nurses report 'something odd')</b>	<b>Yes No</b>	Positive Yes No
---	---------------	-----------------------

**Study number** \_\_\_\_\_

Patient name and hospital number or sticker

**Date** \_\_\_\_\_

### **Screen positive?**

Ask: Would you consider taking part in a research study about mood or memory problems in hospital? Give information sheet and explain as necessary.

### **Assess capacity**

Can the person (free from undue pressure)

- Understand information about the study?
- Retain the information (for long enough to make a decision)?
- Use it to make a decision?
- Communicate the decision?

If yes to all – patient has capacity. If no to any – patient lacks capacity

Patient has capacity: **Yes No**

If yes, ask patient if they are willing to take part, and take formal consent? Ask patient if you could talk to a family member or carer. Then contact carer for carer-participant consent.

If no, contact carer, seek assent and carer-participant consent.

### **Reason for not including in trial**

Patient refused to be screened (CR)

Unable to screen: off ward, care being given, asleep

No carers / family member involved in care (NC)

Discharge home imminent/transfer to non study ward (ND)

No English or reliable interpreter (NE)

Incorrectly put on screening log (LTP)

Unable to contact carers (NR)

Patient refused consent to study

Carer refused consent to study

**Appendix 4: MCOP-BMH Initial Questionnaire**

**Study ID .....**

<b>Date</b>	
<b>Gender</b>	Male <input type="checkbox"/> Female <input type="checkbox"/>
<b>Consent / assent</b>	Consent <input type="checkbox"/> Carer consultee <input type="checkbox"/>

**Questionnaire completed by:**

Please tick one box

The patient participant .....

Jointly by the patient participant and carer

Someone else:

**Who ?**      husband or wife .....

                  another relative (please specify in the box below).....

                  a friend.....

                  a paid carer.....

                  any other (please specify in the box below).....

**A. Living arrangements.** If someone is completing the questionnaire on behalf of the patient participant, please give THE ANSWERS THE PATIENT PARTICIPANT WOULD GIVE if they were able.

**1. Is the patient participant currently**

Please tick one box

- married or have a partner?.....
- divorced or separated?.....
- widowed?.....
- never married?.....

**2. Does the patient participant currently:**

Please tick one box

- live alone?.....
- live with a spouse, other relative, friend or companion?.....
- live in a care home (nursing)?.....
- live in a care home (residential)?.....
- live in a care home (mixed nursing and residential)?.....

**3. What is the highest level of education the patient participant achieved?**

Please tick one box

- Primary school education.....
- Secondary school education, age 14.....
- Ask separately* Secondary school, older than 14 .....
- Vocational education.....  University/higher education.....

**Sections to be completed by direct interview with the participant**

**B. General health**

**[Econ] 1. In comparison with other people of the same age, how do you consider your health?**

- Not as good
- As good
- Better
- Does not know

**[SOF] 6. Do you currently feel full of energy?**

*Please tick one box*

- Yes.....
- No.....

**[EQ5D] 4. Pain / Discomfort: Do you currently have any pain or discomfort?**

*Please tick one box*

- I have no pain or discomfort.....
- I have moderate pain or discomfort.....
- I have extreme pain or discomfort.....

**C. Cognition:** Will you do a memory test for me?

[MMSE]

**ORIENTATION**

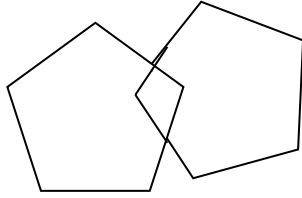
What is the year, season, month, date, day (write down date response)

**/ 5**

Where are we: country, county, town, hospital, ward	<b>/5</b>
<b>MEMORY REGISTRATION</b>	
Examiner names 3 objects (apple, table, penny)  Patient asked to repeat the 3 names – score one for each correct answer  Then patient to learn 3 names (i.e. repeat until correct)	<b>/3</b>
<b>ATTENTION AND CALCULATION</b>	
Subtract 7 from 100, then repeat from result etc. Stop after 5.  100 93 86 79 72 65  (Alternatively, spell “world” backwards. D L R O W)	<b>/5</b>
<b>RECALL</b>	
Ask for 3 objects learnt earlier	<b>/3</b>
<b>LANGUAGE</b>	
Name a pencil and watch	<b>/2</b>
Repeat “No, ifs, ands, or buts”	<b>/1</b>
Give a 3-stage command. Score one point for each correct stage.  (e.g. “take the paper in your right hand, fold it in two and put it on the floor”)	<b>/3</b>
Ask the patient to read and obey a written command on a piece of paper, stating: “close your eyes”.	<b>/1</b>
Ask the patient to write a sentence. Score if it is sensible and has a subject and a verb.	<b>/1</b>

**COPYING**

Ask the patient to copy a pair of intersecting pentagons



**/1**

**TOTAL SCORE**

**/30**

**CLOSE YOUR EYES**



Score the following items from the MMSE results, and carer report (but note different criteria for scoring date)

**[DRS] 9. Orientation.** (Note specific (and liberal) definition of orientation to person)

Disorientation to person means not recognizing familiar persons and may be intact even if the person has naming difficulty but recognizes the person. Disorientation to person is most severe when one doesn't know one's own identity and is rare. Disorientation to person usually occurs after disorientation to time and/or place. Patients who cannot speak can be given a visual or auditory presentation of multiple choice answers. Allow patient to be wrong by up to 7 days instead of 2 days for patients hospitalized more than 3 weeks.

<i>Score</i>		<b><i>Please tick one box</i></b>
0	Oriented to person, place and time .....	<input type="checkbox"/>
1	Disoriented to time (e.g., by more than 2 days or wrong month or wrong year) or to place (e.g., name of building, city, state), but not both .....	<input type="checkbox"/>
2	Disoriented to time and place	<input type="checkbox"/>
3	Disoriented to person	<input type="checkbox"/>

**[DRS] 11. Short-term memory.**

Defined as recall of information (e.g. 3 items presented either verbally or visually) after a delay of about 2 to 3 minutes. When formally tested, information must be registered adequately before recall is tested. The number of trials to register as well as effect of cueing can be noted on scoresheet. Patient should not be allowed to rehearse during the delay period and should be distracted during that time. Patient may speak or nonverbally communicate to the examiner the identity of the correct items. Short-term deficits noticed during the course of the interview can be used also.

<i>Score</i>		<b><i>Please tick one box</i></b>
0	Short-term memory intact	<input type="checkbox"/>
1	Recalls 2/3 items; maybe able to recall third item after category cueing	<input type="checkbox"/>
2	Recalls 1/3 items; may be able to recall other items after category cueing	<input type="checkbox"/>
3	Recalls 0/3 items .....	<input type="checkbox"/>

**[DRS] 12. Long-term memory [DRS].** (*Try current news items, children, medical history*)

Can be assessed formally or through interviewing for recall of past personal (e.g. past medical history or information or experiences that can be corroborated from another source) or general information that is culturally relevant. When formally tested, use a verbal and/or visual modality for 3 items that are adequately registered and recalled after at least 5 minutes. The patient should not be allowed to rehearse during the delay period during formal testing. Make allowances for patients with less than 8 years of education or who are mentally retarded regarding general information questions. Rating of the severity of deficits may involve a judgment about all the ways long-term memory is assessed, including recent and/or remote long-term memory ability informally tested during the interview as well as any formal testing of recent long-term memory using 3 items.

score

***Please tick one box***

- |   |   |                          |
|---|---|--------------------------|
| 0 | No significant long-term memory deficits .....  | <input type="checkbox"/> |
| 1 | Recalls 2 /3 items and/ or has minor difficulty recalling details of other long-term information<br>..... | <input type="checkbox"/> |
| 2 | Recalls 1/3 items and/ or has moderate difficulty recalling other long-term information                   | <input type="checkbox"/> |
| 3 | Recalls 0/3 items and/or has severe difficulty recalling other long-term information.<br>.....            | <input type="checkbox"/> |

**This section onwards is to be completed by direct interview with the patient participant and/or carer on their behalf**

**D. Sleep.** How do you sleep? Do you get up in the night? Is that only for the toilet or due to pain? Are you sleepy in the day?

<p><b>[NPI] 11. Sleep:</b> Does the subject have difficulty sleeping? Is he or she up at night (not including getting up once or twice to the toilet)? Does he/she get up at night thinking it is day? Is he /she sleepy during the day?</p>	<p style="text-align: right;">Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<p>If yes, how often do these problems occur</p>	<p style="text-align: right;">Occasionally (&lt;once a week) <input type="checkbox"/> Often (about once a week) <input type="checkbox"/> Frequent (several times a week but less than every day) <input type="checkbox"/> Very frequent (every night) <input type="checkbox"/></p>
<p>And how severe are the problems?</p>	<p>Mild (night time behaviours occur but are not particularly disruptive) <input type="checkbox"/></p> <p>Moderate (night time behaviours occur and disturb the subject and the sleep of the carer; more than one type of night time behaviour may be present) <input type="checkbox"/></p> <p>Marked (night time behaviour occurs; several types of night time behaviour may be present; the subject is very distressed during the night and the sleep of the carer very disturbed) <input type="checkbox"/></p>

<p><b>[CSDD] D: CYCLIC FUNCTIONS; RW rating</b></p>			
	<p style="text-align: center;"><b>0= not present</b></p>	<p style="text-align: center;"><b>1= mild or intermittent</b></p>	<p style="text-align: center;"><b>2= severe</b></p>

<b>13. Difficulty falling asleep</b>  Later than usual for this individual			
<b>14. Multiple awakenings during sleep</b>			
<b>15. Early morning awakenings</b>  Earlier than usual for this individual			

**[DRS] 1. Sleep wake cycle disturbance.**

Rate sleep-wake pattern using all sources of information, including from family, caregivers, nurses' reports, and patient. Try to distinguish sleep from resting with eyes closed

score

*Please tick one box*

- 0 Not present .....
- 1 Mild sleep continuity disturbance at night or occasional drowsiness during the day ..
- 2 Moderate disorganisation of sleep-wake cycle (e.g. falling asleep during conversations, napping during the day or several brief awakenings during the night with confusion/behavioural changes or very little night time sleep) .....
- 3 Severe disruption of sleep wake cycle (e.g. day-night reversal of sleep wake cycle, or severe circadian fragmentation with multiple periods of sleep and wakefulness or severe sleeplessness) .....

[CSDD] C: PHYSICAL SIGNS; RW rating			
	0= not present	1= mild or intermittent	2= severe
<b>11. Lack of energy</b>  Fatigues easily, unable to sustain activities (score only if change occurred acutely i.e. in less than 1 month)			

**E. Appetite and weight loss** (*rate appetite, swallowing and physical feeding problems*)

<p><b>[NPI] 12. Appetite:</b> Has the subject's appetite or eating habits changed? Has he/she lost or gained weight, or changed the foods he/she likes?</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<p>If yes, how often do these problems occur</p>	<p>Occasionally (&lt; once a week) <input type="checkbox"/></p> <p>Often (about once a week) <input type="checkbox"/></p> <p>Frequent (several times a week but less than every day) <input type="checkbox"/></p> <p>Very frequent (once a day or more) <input type="checkbox"/></p>
<p>And how severe are the problems?</p>	<p>Mild (change in appetite or eating habits is present but has not led to change in weight &amp; is not disturbing) <input type="checkbox"/></p> <p>Moderate (change in appetite or eating habits is present &amp; cause minor change in weight) <input type="checkbox"/></p> <p>Marked (obvious changes in appetite or eating habits are present and cause weight change; is embarrassing or otherwise disturbs the subject) <input type="checkbox"/></p>

**[PCI, MNA] 7. Has your food intake declined over the past 3 months due to loss of appetite, digestive problems, chewing or swallowing difficulties?**

***Please tick one box***

Severe loss of appetite (eats less than ¼ of meal).....

Moderate loss of appetite (eats less than normal but more than ¼ of meal) .....

No loss of appetite.....

**[SOF, MNA] 8. Have you lost weight unintentionally in the last three months?**

***Please tick one box***

Yes.....

No.....

**[PCI] 9. If you have lost weight during the last three months, how much weight have you lost?**

Please complete one box

Weight loss (please state in kilograms: 1kg = 2.2 lb; 1 stone = 6.4 kg)

Do not know.....

[CSDD] C: PHYSICAL SIGNS; RW rating			
	0= not present	1= mild or intermittent	2= severe
<b>9. Appetite loss</b> Eating less than usual			
<b>10. Weight loss</b> (score 2 if greater than 2kg in one month)			

**F. Activities of daily living.** Please score what the patient participant has actually done in the last week or so.

**[Barthel index items]**

[PCI] How has the subject managed with their personal hygiene over the last 7 days?		Independent <input type="checkbox"/>	
		Supervised <input type="checkbox"/>	
		Limited assistance <input type="checkbox"/> Extensive assistance <input type="checkbox"/>	
		Total Dependence <input type="checkbox"/>	
How do they manage with grooming?	Needs help with personal care	0	
	Independent face/hair/teeth/shaving (implements provided)	1	
[PCI] With regards to eating over the last seven days in particular, how has the subject managed?		Independent <input type="checkbox"/>	
		Supervised <input type="checkbox"/>	
		Limited assistance <input type="checkbox"/>	
		Extensive assistance <input type="checkbox"/>	
		Total Dependence <input type="checkbox"/>	
How do they manage with eating?	Unable	0	
	Needs help cutting, spreading butter etc.	1	
	Independent (food provided in reach)	2	
How do they manage with dressing?	Dependent	0	
	Needs help but can do about half unaided	1	
	Independent (including buttons, zips, laces etc.)	2	
How do they manage with bathing?	Dependent	0	
	Independent (or in shower)	1	
[PCI] How has the subject managed with using the toilet over the last 7 days?		Independent <input type="checkbox"/>	
		Supervised <input type="checkbox"/>	
		Limited assistance <input type="checkbox"/> Extensive assistance <input type="checkbox"/>	

		Total Dependence <input type="checkbox"/>	
How do they manage using the toilet?	Dependent	0	
	Needs some help but can do something alone	1	
	Independent (on and off, dressing, wiping)	2	
How do they manage with their bladder?	Incontinent or catheterised and unable to manage	0	
	Occasional accident (max once per 24 hours)	1	
	Continent (for over 7 days)	2	
How do they manage with their bowels?	Incontinent (or needs to be given enema)	0	
	Occasional accident (once per week)	1	
	Continent	2	

**[EQ5D] 2. Self care**

Please tick one box

- I am unable to wash or dress myself.....
- I have some problems in washing or dressing.....
- I have no-problems with looking after myself.....

**[EQ5D] 3. Usual activities (e.g. housework, leisure, family)?**

Please tick one box

- I am unable to perform my usual activities.....
- I have some problems performing my usual activities.....
- I have no problems performing my usual activities.....



## G. Mobility.

### [Barthel index items]

<p><b>[MNA]</b> With regard to mobility, is the subject?</p>	<p>Bed or chair bound <input type="checkbox"/></p> <p>Able to get out of bed/chair but does not go out <input type="checkbox"/></p> <p>Goes out <input type="checkbox"/></p>		
<p><b>[PCI]</b> Over the last seven days in particular, how has the subject been with regard to mobility?</p>	<p>Independent <input type="checkbox"/></p> <p>Supervised <input type="checkbox"/></p> <p>Limited assistance <input type="checkbox"/></p> <p>Extensive assistance <input type="checkbox"/></p> <p>Total Dependence <input type="checkbox"/></p>		
<p>How do they manage with transferring?</p>	<p>Unable - no sitting balance</p>	<p>0</p>	
	<p>Major help (one or two people, physical) can sit</p>	<p>1</p>	
	<p>Minor help (verbal or physical)</p>	<p>2</p>	
	<p>Independent</p>	<p>3</p>	
<p>How do they manage with mobility?</p>	<p>Immobile</p>	<p>0</p>	
	<p>Wheelchair independent including corners etc.</p>	<p>1</p>	
	<p>Walks with help of one person (verbal or physical)</p>	<p>2</p>	
	<p>Independent (but may use any aid e.g. stick)</p>	<p>3</p>	
<p>How do they manage with stairs?</p>	<p>Unable</p>	<p>0</p>	
	<p>Needs help (verbal, physical, carrying aid)</p>	<p>1</p>	
	<p>Independent up and down</p>	<p>2</p>	

### [EQ5D] 1. Mobility

	<i>Please tick one box</i>
I am confined to bed.....	<input type="checkbox"/>
I have some problems in walking about.....	<input type="checkbox"/>
I have no problems walking about.....	<input type="checkbox"/>

**H. Mood and anxiety**

<b>[NPI] 4. Depression:</b> does the subject seem sad or depressed? Does he or she say that he or she feels sad or depressed? Or a burden, a failure or a bad person? Or say he/she wishes to die or harm him/herself?	Yes <input type="checkbox"/> No <input type="checkbox"/>
If yes, how often do these problems occur?	Occasionally (<once a week) <input type="checkbox"/> Often (about once a week) <input type="checkbox"/> Frequent (several times a week but less than every day) <input type="checkbox"/> Very frequent (once a day or more) <input type="checkbox"/>
And how severe are the problems?	Mild (depression is distressing but usually responds to distraction or reassurance) <input type="checkbox"/>  Moderate (depression is distressing, depressive thoughts are spontaneously spoken by the subject and difficult to alleviate) <input type="checkbox"/>  Marked (depression is very distressing, & a major source of suffering for the subject) <input type="checkbox"/>

<p><b>[NPI] 5. Anxiety:</b> Is the subject nervous, anxious, worried or frightened? Is he/she shaky, tense or fidgety? Is he/she afraid to be in particular places or apart from familiar people?</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<p>If yes, how often do these problems occur?</p>	<p>Occasionally (&lt;once a week) <input type="checkbox"/></p> <p>Often (about once a week) <input type="checkbox"/></p> <p>Frequent (several times a week but less than every day) <input type="checkbox"/></p> <p>Very frequent (once a day or more) <input type="checkbox"/></p>
<p>And how severe are the problems?</p>	<p>Mild (anxiety is distressing but usually responds to distraction or reassurance) <input type="checkbox"/></p> <p>Moderate (anxiety is distressing, anxiety symptoms are spontaneously voiced by the subject and difficult to alleviate) <input type="checkbox"/></p> <p>Marked (anxiety is very distressing &amp; a major source of suffering for the subject) <input type="checkbox"/></p>

<p><b>[EQ5D] 5. Anxiety / Depression</b></p>	
	<p><b><i>Please tick one box</i></b></p>
<p>I am not anxious or depressed.....</p>	<p><input type="checkbox"/></p>
<p>I am moderately anxious or depressed.....</p>	<p><input type="checkbox"/></p>
<p>I am extremely anxious or depressed.....</p>	<p><input type="checkbox"/></p>

<p><b>[CSDD] A: MOOD RELATED SIGNS; RW rating</b></p>			
	<p><b>0= not present</b></p>	<p><b>1= mild or intermittent</b></p>	<p><b>2= severe</b></p>
<p><b>1. Anxiety</b> Anxious expression, ruminations, worrying</p>			
<p><b>2. Sadness</b> Sad expression, sad voice, tearfulness</p>			

<b>3. Lack of reactivity to pleasant events</b>			
<b>16. Suicide</b> Feels life is not worth living, has suicidal wishes, or made suicide attempt			
<b>17. Poor self esteem</b> Self blame, self depreciation, feelings of failure			
<b>18. Pessimism</b> Anticipation of the worst			

<b>[NPI] 7. Apathy and indifference:</b> has the subject lost interest in the world around him/her? Does he or she seem less interested in his/her usual activities and in other people? Or become less likely to start a conversation? Or seems not to have any motivation or not to care about things any more?	Yes <input type="checkbox"/> No <input type="checkbox"/>
If yes, how often do these problems occur?	Occasionally (<once a week) <input type="checkbox"/> Often (about once a week) <input type="checkbox"/> Frequent (several times a week but less than every day) <input type="checkbox"/> Very frequent (once a day or more) <input type="checkbox"/>
And how severe are the problems?	Mild (apathy is noticeable but produces little interference with daily life; only slightly different from usual behaviour; subject responds to suggestions to do things) <input type="checkbox"/>  Moderate (apathy is very evident; may be overcome with coaxing and encouragement; responds spontaneously only to powerful events such as family visits) <input type="checkbox"/>  Marked (apathy is very evident and usually fails to respond to any encouragement or external events) <input type="checkbox"/>

<b>[CSDDD] B: BEHAVIOURAL DISTURBANCE; RW rating</b>			
	<b>0= not present</b>	<b>1= mild or intermittent</b>	<b>2= severe</b>

<b>8. Loss of interest</b>  Less involved in usual activities (score only if change occurred acutely i.e. in less than 1 month)			
---	--	--	--

**[DRS] 4. Lability of affect** (do mood and emotions vary, are they under control and appropriate?).

Rate the patient's affect as the outward presentation of emotions and not as a description of what the patient feels.

score *Please tick one box*

0 Not present .....

1 Affect somewhat altered or incongruent to situation; changes over the course of hours; emotions are mostly under self-control .....

2 Affect is often inappropriate to the situation and intermittently changes over the course of minutes; emotions are not consistently under self-control, though they respond to redirection by others .....

3 Severe and consistent disinhibition of emotions; affect changes rapidly, is inappropriate to context, and does not respond to redirection by others ....

<b>[CSDD] D: CYCLIC FUNCTIONS; RW rating</b>			
	<b>0= not present</b>	<b>1= mild or intermittent</b>	<b>2= severe</b>
<b>12. Diurnal variation of mood</b>  Symptoms worse in the morning			

<b>[NPI] 6. Elation:</b> does the subject seem abnormally cheerful or happy for no reason? Does he/she find things funny that others don't? Or tell silly jokes, or play tricks or pranks? Or boast about abilities or wealth?	Yes <input type="checkbox"/> No <input type="checkbox"/>
If yes, how often do these problems occur	Occasionally (<once a week) <input type="checkbox"/> Often (about once a week) <input type="checkbox"/> Frequent (several times a week but less than every day) <input type="checkbox"/> Very frequent (once a day or more) <input type="checkbox"/>

And how severe are the problems?	Mild (elation is noticeable by friends and family but is not disruptive) <input type="checkbox"/>  Moderate (elation is noticeably abnormal) <input type="checkbox"/>  Marked (elation is very pronounced; subject is euphoric and finds everything to be funny) <input type="checkbox"/>
----------------------------------	---

<b>[NPI]: 8. Disinhibition:</b> does the subject seem to act impulsively without thinking about the consequences? Does he/she talk to strangers as if he or she knows them? Or say or do things that are rude or embarrassing? Or hurt people's feelings?	Yes <input type="checkbox"/> No <input type="checkbox"/>
If yes, how often do these problems occur?	Occasionally (<once a week) <input type="checkbox"/> Often (about once a week) <input type="checkbox"/> Frequent (several times a week but less than every day) <input type="checkbox"/> Very frequent (once a day or more) <input type="checkbox"/>
And how severe are the problems?	Mild (behaviour is noticeable but usually responds to distraction or reassurance) <input type="checkbox"/>  Moderate (behaviour is very evident and difficult to overcome by carer) <input type="checkbox"/>  Marked (behaviour usually fails to respond to any intervention by carer and is a source of embarrassment or social distress) <input type="checkbox"/>

<b>H. Agitation, irritability, increased or decreased motor activity</b>
--

<b>[NPI] 9. Irritability and temper:</b> does the subject get irritated easily? Or impatient? Do his/her moods change quickly? Does he/she get bad	Yes <input type="checkbox"/> No <input type="checkbox"/>
--	--

tempered? Or angry or argumentative?	
If yes, how often do these problems occur?	Occasionally (<once a week) <input type="checkbox"/> Often (about once a week) <input type="checkbox"/> Frequent (several times a week but less than every day) <input type="checkbox"/> Very frequent (once a day or more) <input type="checkbox"/>
And how severe are the problems?	Mild (irritability or moodiness is noticeable but usually responds to distraction or reassurance) <input type="checkbox"/>  Moderate (irritability or moodiness is very evident and difficult to overcome by carer) <input type="checkbox"/>  Marked (irritability or moodiness is very evident, usually fails to respond to any intervention by carer and they are a major source of distress) <input type="checkbox"/>

<b>[CSDD] A: MOOD RELATED SIGNS; RW rating</b>			
	<b>0= not present</b>	<b>1= mild or intermittent</b>	<b>2= severe</b>
<b>4. Irritability.</b>  Easily annoyed, short tempered			

<b>[NPI] 3. Agitation and Aggression:</b> does the subject have periods when he/she is agitated or aggressive? Or refuses to co-operate? Or won't let people help him/her with washing or dressing? Or shout or swear?	Yes <input type="checkbox"/> No <input type="checkbox"/>
If yes, how often do these problems occur?	Occasionally (<once a week) <input type="checkbox"/> Often (about once a week) <input type="checkbox"/> Frequent (several times a week but less than every day) <input type="checkbox"/> Very frequent (once a day or more) <input type="checkbox"/>
And how severe are the problems?	Mild (behaviour is disruptive but can be managed with distraction or reassurance) <input type="checkbox"/>

	Moderate (behaviour is disruptive and difficult to distract or control) <input type="checkbox"/>  Marked (agitation is very disruptive and a major source of difficulty; there may be a threat of personal harm) <input type="checkbox"/>
--	---

<b>[NPI] 10. Motor behaviour:</b> does the subject pace around or wander? Or engage in repetitive activities, such as opening cupboards or drawers, or picking at things, or winding threads?	Yes <input type="checkbox"/> No <input type="checkbox"/>
If yes, how often do these problems occur	Occasionally (<once a week) <input type="checkbox"/> Often (about once a week) <input type="checkbox"/> Frequent (several times a week but less than every day) <input type="checkbox"/> Very frequent (once a day or more) <input type="checkbox"/>
And how severe are the problems?	Mild (behaviour is noticeable but produces little interference with daily life) <input type="checkbox"/> Moderate (behaviour is very evident but can be overcome by carer) <input type="checkbox"/> Marked (behaviour is very evident and usually fails to respond to any intervention by carer & is a major source of distress) <input type="checkbox"/>

<b>[DRS] 7. Motor agitation.</b> Rate by observation, including from other sources of observation such as by visitors, family and clinical staff. Do not include dyskinesia, tics, or chorea. <i>score</i>	
	<b><i>Please tick one box</i></b>
0	No restlessness or agitation ..... <input type="checkbox"/>
1	Mild restlessness of gross motor movements or mild fidgetiness <input type="checkbox"/>
2	Moderate motor agitation including dramatic movements of the extremities, pacing, fidgeting, removing intravenous lines, etc <input type="checkbox"/>
3	Severe motor agitation, such as combativeness or a need for restraints or seclusion <input type="checkbox"/>

<b>[DRS] 8. Motor retardation.</b> Rate movement by direct observation or from other sources of observation such as family, visitors, or clinical staff. Do not rate components of retardation that are caused by parkinsonian symptoms. Do not rate drowsiness or sleep. <i>score</i>	
	<b><i>Please tick one box</i></b>



0	No slowness of voluntary movements .....	<input type="checkbox"/>
1	Mildly reduced frequency, spontaneity or speed of motor movements, to the degree that may interfere somewhat with the assessment.	<input type="checkbox"/>
2	Moderately reduced frequency, spontaneity or speed of motor movements to the degree that it interferes with participation in activities or self-care	<input type="checkbox"/>
3	Severe motor retardation with few spontaneous movements.....	<input type="checkbox"/>

[CSDD] B: BEHAVIOURAL DISTURBANCE; RW rating			
	0= not present	1= mild or intermittent	2= severe
<b>5. Agitation</b> Restlessness, hand-wringing, hair-pulling			
<b>6. Retardation</b> Slow movements, slow speech, slow reactions			
<b>7. Multiple physical complaints</b> (score 0 if GI symptoms only)			

**I. Delusions and hallucinations**

<b>[NPI] 1. Delusions:</b> does the subject have beliefs that you know are not true?	Yes <input type="checkbox"/> No <input type="checkbox"/>
If yes, how often do these problems occur?	Occasionally (<once a week) <input type="checkbox"/> Often (about once a week) <input type="checkbox"/> Frequent (several times a week but less than every day) <input type="checkbox"/> Very frequent (once a day or more) <input type="checkbox"/>
And how severe are the problems?	Mild (beliefs present but seem harmless and produce little distress) <input type="checkbox"/> Moderate (beliefs are distressing and disruptive) <input type="checkbox"/> Marked (beliefs are very disruptive & are a major source of disturbed behaviour) <input type="checkbox"/>

[CSDD] E. IDEATIONAL DISTURBANCE; RW rating			
	0= not present	1= mild or intermittent	2= severe
<b>19. Mood congruent (<i>depressive, manic</i>) delusions</b>			
Delusions of poverty, illness, or loss			

**[DRS] 3. Delusions.**

Delusions can be of any type, but are most often persecutory. Rate if reported by patient, family or caregiver. Rate as delusional if ideas are unlikely to be true yet are believed by the patient who cannot be dissuaded by logic. Delusional ideas cannot be explained otherwise by the patient's usual cultural or religious background.

score *Please tick one box*

0 Not present .....

1 Mildly suspicious, hypervigilant, or preoccupied .....

2 Unusual or overvalued ideation that does not reach delusional proportions or could be plausible .....

3 Delusional .....

<b>[NPI] 2. Hallucinations:</b> does the subject have hallucinations, such as false visions or voices?	Yes <input type="checkbox"/> No <input type="checkbox"/>
If yes, how often do these problems occur?	Occasionally (<once a week) <input type="checkbox"/> Often (about once a week) <input type="checkbox"/> Frequent (several times a week but less than every day) <input type="checkbox"/> Very frequent (once a day or more) <input type="checkbox"/>
And how severe are the problems?	Mild (hallucinations present but seem harmless and produce little distress) <input type="checkbox"/> Moderate (hallucinations are distressing and disruptive) <input type="checkbox"/> Marked (hallucinations are very disruptive & are a major source of disturbed behaviour) <input type="checkbox"/>

**[DRS] 2. Perceptual disturbances and hallucinations.**

Illusions and hallucinations can be of any sensory modality. Misperceptions are "simple" if they are uncomplicated, such as a sound, noise, colour, spot, or flashes and "complex" if they are multidimensional, such as voices, music, people, animals, or scenes. Rate if reported by patient or caregiver, or inferred by observation

score

*Please tick one box*

- |   |   |                          |
|---|---|--------------------------|
| 0 | Not present .....   | <input type="checkbox"/> |
| 1 | Mild perceptual disturbances (e.g., feelings of derealization or depersonalization; or patient may not be able to discriminate dreams from reality) ..... | <input type="checkbox"/> |
| 2 | Illusions present .....   | <input type="checkbox"/> |
| 3 | Hallucinations present .....  | <input type="checkbox"/> |

**J. Delirium diagnostic items.**

**[DRS] 14. Temporal onset of symptoms** (*Rate change in mental state or behaviour*).

Rate the acuteness of onset of the initial symptoms of the disorder or episode being currently assessed, not their total duration. Distinguish the onset of symptoms attributable to delirium when it occurs concurrently with a different preexisting psychiatric disorder. For example, if a patient with major depression is rated during a delirium episode due to an overdose, then rate the onset of the delirium symptoms.

score

*Please tick one box*

- |   |  |                          |
|---|--|--------------------------|
| 0 | No significant change from usual or longstanding baseline behaviour ...          | <input type="checkbox"/> |
| 1 | Gradual onset of symptoms, occurring over a period of several weeks to a month   | <input type="checkbox"/> |
| 2 | Acute change in behaviour or personality occurring over days to a week           | <input type="checkbox"/> |
| 3 | Abrupt change in behaviour occurring over a period of several hours to a day ... | <input type="checkbox"/> |

**[DRS] 15. Fluctuation of symptom severity.** (*Apply to any mental or psychological symptoms or behaviour*)

Rate the waxing and waning of an individual or cluster of symptom(s) over the time frame being rated. Usually applies to cognition, affect, intensity of hallucinations, thought disorder, language disturbance. Take into consideration that perceptual disturbances usually occur intermittently, but might cluster in period of greater intensity when other symptoms fluctuate in severity,

score

***Please tick one box***

- |   |   |                          |
|---|---|--------------------------|
| 0 | No symptom fluctuation                                | <input type="checkbox"/> |
| 1 | Symptom intensity fluctuates in severity over hours   | <input type="checkbox"/> |
| 2 | Symptom intensity fluctuates in severity over minutes | <input type="checkbox"/> |

**[DRS] 16. Physical disorder** (*any drug, infection, metabolic or brain disorder or other medical problem*).

Rate the degree to which a physiological, medical or pharmacological problem can be specifically attributed to have caused the symptoms being assessed. Many patients have such problems but they may or may not have causal relationship to the symptoms being rated.

score

***Please tick one box***

- |   |   |                          |
|---|---|--------------------------|
| 0 | None present or active.....   | <input type="checkbox"/> |
| 1 | Presence of any physical disorder that might affect mental state  | <input type="checkbox"/> |
| 2 | Drug, infection, metabolic disorder, CNS lesion or other medical problem that specifically can be implicated in causing the altered behaviour or mental state | <input type="checkbox"/> |

**K. Observations from interview.**

**[DRS] 10. Attention.**

Attention can be assessed during the interview (e.g., verbal perseverations, distractibility, and difficulty with set shifting) and /or through use of specific tests, e.g., digit span. Patients with sensory deficits or who are intubated or whose hand movements are constrained should be tested using an alternate modality besides writing.

Score

***Please tick one box***

- |   |  |                          |
|---|--|--------------------------|
| 0 | Alert and attentive .....  | <input type="checkbox"/> |
| 1 | Mildly distractible or mild difficulty sustaining attention, but able to refocus with cueing. On formal testing makes only minor errors and is not significantly slow in responses ..... | <input type="checkbox"/> |
| 2 | Moderate inattention with difficulty focusing and sustaining attention. On formal testing,   |                          |

	makes numerous errors and either requires prodding to focus or finish the task.....	<input type="checkbox"/>
3	Severe difficulty focusing and/or sustaining attention, with many incorrect or incomplete responses or inability to follow instructions. Distractible by other noises or events in the environment .....	<input type="checkbox"/>

**[DRS] 5. Language.**

Rate abnormalities of spoken, written or sign language that cannot be otherwise attributed to dialect or stuttering. Assess fluency, grammar, comprehension, semantic content and naming. Test comprehension and naming nonverbally if necessary by having patient follow commands or point.

score

**Please tick one box**

0	Normal language .....	<input type="checkbox"/>
1	Mild impairment including word-finding difficulty or problems with naming or fluency ...	<input type="checkbox"/>
2	Moderate impairment including comprehension difficulties or deficits in meaningful communication (semantic content) .....	<input type="checkbox"/>
3	Severe impairment including nonsensical semantic content, word salad, muteness, or severely reduced comprehension .....	<input type="checkbox"/>

**[DRS] 6. Thought process abnormalities** (*do thoughts flow logically one to the next, coherence of thought*).

Rate abnormalities of thinking processes based on verbal or written output. If a patient does not speak or write, do not rate this item.

score

**Please tick one box**

0	Normal thought processes .....	<input type="checkbox"/>
1	Tangential or circumstantial .....	<input type="checkbox"/>
2	Associations loosely connected occasionally, but largely comprehensible .....	<input type="checkbox"/>
3	Associations loosely connected most of the time .....	<input type="checkbox"/>

**[DRS] 13. Visuospatial ability** (*use intersecting pentagons, and reports of navigation on ward or at home*)

Assess informally and formally. Consider patient's difficulty navigating one's way around living areas or environment (e.g. getting lost). Test formally by drawing or copying a design, by arranging puzzle pieces, or by drawing a map and identifying major cities, etc. Take into account any visual impairments that may affect performance

Score

**Please tick one box**

0	No impairment .....	<input type="checkbox"/>
1	Mild impairment such that overall design and most details or pieces are correct; and/or little difficulty navigating in his/her surroundings .....	<input type="checkbox"/>
2	Moderate impairment with distorted appreciation of overall design and/or several errors of details or pieces; and/or needing repeated redirection to keep from getting lost in a newer environment despite, trouble locating familiar objects in immediate environment .....	<input type="checkbox"/>
3	Severe impairment on formal testing; and/or repeated wandering or getting lost in environment .....	<input type="checkbox"/>

**L. Help and support received, OVER THE LAST FEW WEEKS.**

**[Econ] 1. How financially well off do you feel in general?**

*Please tick one box*

Very well off.....	<input type="checkbox"/>
Well off .....	<input type="checkbox"/>
Not well off.....	<input type="checkbox"/>

**[Econ] 2. Do you receive pension credit?**

*Please tick one box*

Yes.....	<input type="checkbox"/>
No.....	<input type="checkbox"/>

**[PCI] 3. Have you been admitted to a nursing/care home in the past three months?**

*Please tick one box*

Yes.....	<input type="checkbox"/>
----------	--------------------------

No.....

**[Econ]4. How many different people provide personal or domestic care for you?**   
*(do not answer if in care home)*

**[Econ] 7. Do you attend:**

	<i>Please tick one box</i>	<i>Name of place you attend</i>	<i>If yes, how many times per week</i>
Day centre/hospital	Yes <input type="checkbox"/> No <input type="checkbox"/>	.....	.....
Others (please list)		.....	.....
.....		.....	.....
.....		.....	.....
.....		.....	.....

**[Econ] 5. Do any of the following come in to see you?**

Please tick one box

**If yes, how many times  
per day and times per  
week**

Community care assistant                      Yes  No                       .....

..

Privately organised carer                      Yes  No                       .....

..

Cleaner    Yes  No                       .....

..

Community Matron                              Yes  No                       .....

..

District Nurse                                    Yes  No                       .....

..

Specialist nurse                                 Yes  No                       .....

..

Other (please list)

.....

....

..

.....

....

..

.....

....

..

.....

....

..

**[Econ] 6. How often do you talk to neighbours, friends/relatives, at home/elsewhere?**

*(subjective perception only)*

**Please tick one box**



Very often.....	<input type="checkbox"/>
Often.....	<input type="checkbox"/>
Not very often.....	<input type="checkbox"/>
Never.....	<input type="checkbox"/>

**M. Prior activities of daily living.** Please score what the patient participant actually did prior to the current illness, or 3 months ago if current illness longer than this.

How do they manage with eating?	Unable	0	
	Needs help cutting, spreading butter etc.	1	
	Independent (food provided in reach)	2	
How do they manage with grooming?	Needs help with personal care	0	
	Independent face/hair/teeth/shaving (implements provided)	1	
How do they manage with dressing?	Dependent	0	
	Needs help but can do about half unaided	1	
	Independent (including buttons, zips, laces etc.)	2	
How do they manage with bathing?	Dependent	0	
	Independent (or in shower)	1	
How do they manage using the toilet?	Dependent	0	
	Needs some help but can do something alone	1	
	Independent (on and off, dressing, wiping)	2	
How do they manage with their bladder?	Incontinent or catheterised and unable to manage	0	
	Occasional accident (max once per 24 hours)	1	
	Continent (for over 7 days)	2	

How do they manage with their bowels?	Incontinent (or needs to be given enema)	0	
	Occasional accident (once per week)	1	
	Continent	2	
How do they manage with transferring?	Unable - no sitting balance	0	
	Major help (one or two people, physical) can sit	1	
	Minor help (verbal or physical)	2	
	Independent	3	
How do they manage with mobility?	Immobile	0	
	Wheelchair independent including corners etc.	1	
	Walks with help of one person (verbal or physical)	2	
	Independent (but may use any aid e.g. stick)	3	
How do they manage with stairs?	Unable	0	
	Needs help (verbal, physical, carrying aid)	1	
	Independent up and down	2	

## N. Measurements

Weight (from notes /nursing record if done, estimate if unable to weigh)		
Demispan		
Mid-arm circumference (cm)	Right arm	Left arm
Calf circumference (cm)	Right calf	Left calf
Grip strength	Right	Left

Ability to rise from a chair 5 times without using his/her arms	Yes <input type="checkbox"/> No <input type="checkbox"/>	Time

**The end, thank you!**

**Appendix 5: MCOP-BMH Medical Data Form**

**Study ID .....**

**This section is to be completed from the medical notes of the participant by the researcher**

<b>Has the participant ever had any of the following medical conditions?</b>		
Myocardial infarct	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Congestive heart failure	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Peripheral vascular disease	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Cerebrovascular disease	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Dementia	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Chronic pulmonary disease	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Short of breath	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Connective tissue disease	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Ulcer disease	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Mild liver disease	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Moderate or severe liver disease	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Diabetes	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Hemiplegia	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Moderate or severe renal disease	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Renal failure	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Diabetes with end organ damage	Yes <input type="checkbox"/>	No <input type="checkbox"/>

Any tumour	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Leukaemia	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Lymphoma	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Metastatic solid tumour	Yes <input type="checkbox"/>	No <input type="checkbox"/>
AIDS	Yes <input type="checkbox"/>	No <input type="checkbox"/>

<b>Neuropsychological problems</b>	Severe dementia or depression <input type="checkbox"/>
	Mild dementia or depression <input type="checkbox"/>
	No psychological problems <input type="checkbox"/>

<b>Did the participant present with any of the following:</b>		
Fall	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Reduced mobility	Yes <input type="checkbox"/>	No <input type="checkbox"/>
New or increased continence disorder	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Current pressure sores	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Dehydration	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Deteriorated cognitive skills or status in the past 3 months	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Psychological stress or acute disease in the past 3 months (e.g. bereavement, moved	Yes <input type="checkbox"/>	No <input type="checkbox"/>

home, been sick)	
------------------	--

<b>Admission medications</b>			
<b>Drug</b>	<b>Dose</b>	<b>Frequency</b>	<b>BNF chapter number</b>

<b>Total number of different prescription medications taken each day</b>			

<b>Admission/initial modified early warning score.</b> From observations chart. Please circle.							
score	3	2	2	0	1	2	3
Systolic BP (mmHg)	<70	71-80	81-100	101-199	-	>200	-
Heart rate (bpm)	-	<40	41-50	51-100	101-110	111-129	>130
Respiratory rate	-	<9	-	9-14	15-20	21-29	>30
Temperature (deg C)	-	<35	-	35-38.4	-	>38.5	-
Conscious level (AVPU)	-	-	-	A	V	P	U
Urine output (ml/kg/h)	anuric	<0.5	<1	1-2.5	-	>3	

**Appendix 6: MCOP-BMH Psychiatric Assessment Form**



**Mental Health Problems on Hospital Medical Wards**

**Psychiatric Assessment Proforma**

Study number \_\_\_\_\_ Ward \_\_\_\_\_ Date \_\_\_\_\_

Researcher \_\_\_\_\_ Days since  
admission \_\_\_\_\_

Current and past psychiatric history, cognitive history (**free text, not for coding**;  
see Psychiatric Diagnostic Study History Schedule )



Study number \_\_\_\_\_ Date \_\_\_\_\_

**Please complete following ICD-10 diagnoses**

**1. Delirium present:**

definitely ; probably ; possibly ; not present ; not known ; not applicable

**Superimposed on dementia:** definitely ; probably ; possibly ; not

Cause(s) of delirium evident: yes  no  Specify

**Induced by alcohol or other psycho active substance:** yes  no  Specify

Significant behaviour problem posed in present care setting:

mild  moderate  severe  none

Specify:

Hallucinations: yes  no ; Delusions: yes  no

Specify:

**2. Dementia present:**

definitely ; probably ; possibly ; not present ; not known ; not applicable

**MCI**

Potentially reversible cause (specify and justify):

Significant behaviour problem posed in present care setting:

mild  moderate  severe  none

Specify:

Hallucinations: yes  no ; Delusions: yes  no

Specify:

Study number \_\_\_\_\_ Date \_\_\_\_\_

### 3. Dementia Subtype

Alzheimer's disease present:

Definitely ; probably ; possibly ; not present ; not known ; not applicable

Vascular dementia disease present:

Definitely ; probably ; possibly ; not present ; not known ; not applicable

Dementia with Lewy Bodies present:

Definitely ; probably ; possibly ; not present ; not known ; not applicable

FTD disease present:

Definitely ; probably ; possibly ; not present ; not known ; not applicable

Mixed dementia present: Specify:

Definitely ; probably ; possibly ; not present ; not known ; not applicable

Other dementia present: Specify:

Definitely ; probably ; possibly ; not present ; not known ; not applicable

### 4. Depression present:

Definitely ; probably ; possibly ; not present ; not known ; not applicable

Severity: mild ; moderate ; severe ; psychotic symptoms

Somatic syndrome: present ; absent

Subtype:

Depressive episode ; dysthymia ; Recurrent depressive disorder ; other (specify)

Hypomania ; Manic episode ; psychotic symptoms

Bipolar affective disorder

### 5. Anxiety present:

definitely  probably  possibly  not present  not known  not applicable

Subtype: generalised anxiety disorder  phobic ; panic

Agoraphobia ; social phobia ; specific (isolated) phobia ; Specify

Mixed anxiety and depressive disorder ; anxiety disorder, unspecified

Obsessive-compulsive disorder ; somatoform disorder ; specify

Study number \_\_\_\_\_

Date \_\_\_\_\_

**6. Delusional disorders** present:

definitely  probably  possibly  not present  not known  not applicable

**Paraphrenia;**

definitely  probably  possibly  not present  not known  not applicable

Significant behaviour problem posed in present care setting:

mild  moderate  severe  none

Specify:

**7. Adjustment disorder** present:

definitely  probably  possibly  not present  not known  not applicable

**Somatisation disorder** present:

definitely  probably  possibly  not present  not known  not applicable

**8. Mental and behavioural disorders due to psychoactive substance** use (including alcohol), present:

definitely  probably  possibly  not present  not known  not applicable

Specify

**9. Other disorder** present:

Definitely  probably  possibly  not present  not known  not applicable

Specify and justify :

Study number \_\_\_\_\_

Date \_\_\_\_\_

**10. Current interventions**

Record perception of what are the treating team's current "psychiatric interventions", if any?)

**Drug therapy** for mental health condition yes  no

Appropriate drug  Appropriate dose  Evidence of assessment for effectiveness

**Behavioural interventions**

Evidence of restraint: bedrails  other  specify

Evidence of restriction yes  no  specify

Other yes  no  specify

**Other specific interventions; specify**

Study number \_\_\_\_\_

Date \_\_\_\_\_

**11. Psychiatric Needs Assessment.** Needs = potential to benefit from an intervention. Psychiatrist recommendations for ongoing and further care (all plausible).

These are assessments of the immediate state of need for specialist old age psychiatric service made at the end of the psychiatric diagnostic assessment, taking account of the clinical data therein gained and of already available information otherwise gathered by the study. There are twin foci:

- firstly on need for service intervention and
- secondly on need for one of (or a variety of) possible therapeutic interventions, including medication prescription.

These judgements are made by service clinicians in normal service conditions, with the standard expectations of service availability and resourcing to which they have been used.

### Service Interventions

1] patient needs psychiatric assessment ward admission now (this includes MHA detention options and DoLs)	1=yes, 2=no, 8=DK,9=N/A
2] patient needs psychiatric assessment ward admission when physically fit for transfer and must have psychiatric nursing supplied from the psychiatric assessment ward in the interim until that is possible <sup>1</sup> (includes MHA detention options and DoLs)	1=yes, 2=no, 8=DK,9=N/A
3] patient needs psychiatric assessment ward admission when physically fit for transfer and can wait for this without such nursing (includes MHA detention options and DoLs)	1=yes, 2=no, 8=DK,9=N/A
4] patient needs 2 <sup>nd</sup> . or further psychiatric review in order to determine need for psychiatric assessment ward admission (includes MHA detention options and DoLs)	1=yes, 2=no, 8=DK,9=N/A
5] patient does not need psychiatric assessment ward admission now but needs further psychiatric review on ward further to assess progress and such possible need later	1=yes, 2=no, 8=DK,9=N/A
6] patient needs psychiatrist follow up by the service post general hospital discharge (& this does not exclude 6], below)	1=yes, 2=no, 8=DK,9=N/A
7] patient needs non-psychiatrist follow up/further/additional intervention by the service (e.g. CPN, clinical psychologist, OT, Physio.) post general hospital (GH) discharge. If so,	1=yes, 2=no, 8=DK,9=N/A

specify which and more than one may be specified	
8] GP needs positively to review need for further psychiatric involvement post GH discharge	1=yes, 2=no, 8=DK,9=N/A
9] patient does not need follow up by the specialist psychiatric service post general hospital discharge	1=yes, 2=no, 8=DK,9=N/A

Study number \_\_\_\_\_

Date \_\_\_\_\_

**Therapeutic Interventions**

1] Suggest start or continue (without dose modification) antipsychotic drug	1=yes, 2=no, 8=DK,9=N/A
If yes, specify BNF group, drug and route of administration: BNF Group (Group code), BNF name, Administration route	Code: Name: Route: oral solid/ oral liquid / im /depot /iv /pr
2] Suggest modification of present antipsychotic drug	1=yes, 2=no, 8=DK,9=N/A
specify BNF group, drug and route of administration: BNF Group (Group code), BNF name, Administration route	Code: Name: Route: oral solid/ oral liquid /im /depot /iv /pr
3] as 1] & 2] for Hypnotic, Anxiolytics, or Antidepressant drugs, drugs used for prophylaxis of bipolar disorder, drugs used in parkinsonism for prophylaxis or treatment of drug side effects of antipsychotics, drugs used for dementia, any other BNF CNS drugs.	1=yes, 2=no, 8=DK,9=N/A
Specify BNF group, drug and route of administration: BNF Group (Group code), BNF name, Administration route	Code: Name: Route: oral solid/ oral liquid /im /depot /iv /pr
	Code: Name: Route: oral solid/ oral liquid /im /depot /iv /pr
	Code: Name: Route: oral solid/ oral liquid /im /depot /iv /pr
4] Refer or list for team CMHT psychiatrist follow up	1=yes, 2=no, 8=DK,9=N/A
5] Refer for team CMHT CPN follow up	1=yes, 2=no, 8=DK,9=N/A
6] Refer for team CMHT follow up by non-CPN member (specify)	1=yes, 2=no, 8=DK,9=N/A
7] Refer for clinical psychologist assessment/intervention	1=yes, 2=no, 8=DK,9=N/A
8] Refer for specialist psychiatric day therapy intervention (based in former psychiatric Day Hospital)	1=yes, 2=no, 8=DK,9=N/A

Study number \_\_\_\_\_

Date \_\_\_\_\_

**Social Interventions**

1] Refer for JackDawe team support (special multiagency social services-led home support for people with dementia)	1=yes, 2=no, 8=DK,9=N/A
2] Refer for intermediate care	1=yes, 2=no, 8=DK,9=N/A
3] Refer for general social services support	1=yes, 2=no, 8=DK,9=N/A
4] Suggest Care Home admission for respite/assessment (specify type)	1=yes, 2=no, 8=DK,9=N/A  NH RH  General Dementia registered
5] Suggest Care Home admission expected to be permanent (specify type)	1=yes, 2=no, 8=DK,9=N/A  NH RH  General Dementia registered

**Service Improvement option**

1] Is there a modification of the present psychiatric service which would enable earlier or more likely discharge home? If so, specify	1=yes, 2=no, 8=DK,9=N/A
2] Is there a modification of the present social services or of integrated support which would enable earlier or more likely discharge home? If so, specify	1=yes, 2=no, 8=DK,9=N/A
3] Is there a modification of the present psychiatric service which would enable earlier or more likely positive therapeutic progress? If so, specify	1=yes, 2=no, 8=DK,9=N/A
4] Is there a modification of the present general hospital service which would enable earlier or more likely positive therapeutic progress? If so, specify	1=yes, 2=no, 8=DK,9=N/A

**Other suggested mental health intervention**




**Appendix 7: MCOP-BMH Medical Assessment Form**

**Study number** \_\_\_\_\_ **Ward** \_\_\_\_\_ Day of admission assessed \_\_\_\_\_

**Researcher** \_\_\_\_\_ **Date** \_\_\_\_\_

**1. Diagnostic assessment (include psychiatric).** Include all diagnosable conditions of any clinical relevance.

Certainty based on clinical judgment of evidence; active = causing problem now; potential = may cause problems; inactive= no current or potential problem

Diagnosis	Definite/probable/possible	Active/potential/inactive

Study number \_\_\_\_\_

**2. Problem list.** Include relevant and 'active' issues, including symptoms, impairments, disabilities, risks, risk factors, predispositions, behaviours, abnormal investigations. Broadly medical (social and environmental is next).

Explained means credible and sufficient explanation for problem.

Problem	Explained/ diagnosed?

Study number \_\_\_\_\_

Date

**3. Social, environmental and contextual issues.** Relationships, carer strain, available family and external help, accommodation, prior adaptations, use of aids, broad financial situation

Issue
Accommodation/adaptations/ physical environment
Social and family support, including statutory
Finance and resources, including aids, appliances, car
Other



Study number \_\_\_\_\_

**4a. Interventions.** List drugs started and stopped.

<b>Drugs started</b>			
Drug	Dose	frequency	Length of course (estimate, state if ongoing)

<b>Drugs stopped</b>			
Drug	Dose	frequency	

**Study number** \_\_\_\_\_

**5. Needs.** Geriatrician recommendations for ongoing and further care. Include communication /explanation/decision making/discharge planning

Proposed intervention	Who

**Appendix 8: MCOP-BMH Outcome Questionnaire**

**Study ID .....**

Today's date: .....

**Is this form being completed by interview with the patient participant directly?**

*Please tick one box*

Yes, by interview with patient participant alone .....

Yes, by interview with patient participant and carer jointly .....

No, it is being completed by interview with:

    Patient's husband or wife .....

    Another relative (please specify in the box below).....

    A friend.....

    A paid carer.....

    Any other (please specify in the box below).....

**This section is to be completed by direct interview with the patient  
participant only**

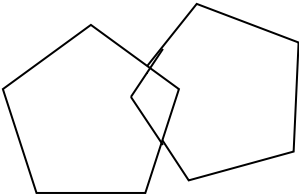
**A. Cognition:** Will you do a memory test for me?

[MMSE]

<b>ORIENTATION</b>	
What is the year, season, month, date, day	<b>/ 5</b>
Where are we: country, county, town, hospital, ward	<b>/5</b>
<b>MEMORY REGISTRATION</b>	
Examiner names 3 objects (apple, table, penny)  Patient asked to repeat the 3 names – score one for each correct answer  Then patient to learn 3 names (i.e. repeat until correct)	<b>/3</b>
<b>ATTENTION AND CALCULATION</b>	
Subtract 7 from 100, then repeat from result etc. Stop after 5.  100 93 86 79 72 65  (Alternatively, spell “world” backwards. D L R O W)	<b>/5</b>
<b>RECALL</b>	
Ask for 3 objects learnt earlier	<b>/3</b>
<b>LANGUAGE</b>	
Name a pencil and watch	<b>/2</b>
Repeat “No, ifs, ands, or buts”	<b>/1</b>



<p>Give a 3-stage command. Score one point for each correct stage.  (e.g. "take the paper in your right hand, fold it in two and put it on the floor")</p>	<b>/3</b>
<p>Ask the patient to read and obey a written command on a piece of paper, stating: "close your eyes".</p>	<b>/1</b>
<p>Ask the patient to write a sentence. Score if it is sensible and has a subject and a verb.</p>	<b>/1</b>

<b>COPYING</b>	
<p>Ask the patient to copy a pair of intersecting pentagons</p> <div style="text-align: center; margin: 20px 0;">  </div>	<b>/1</b>
<b>TOTAL SCORE</b>	<b>/30</b>

**B. DEMQoL Quality of life.** Now I would like to ask about how you find life at present. Look at the card to choose which answer describes how you feel.

First, I'm going to ask you about **your feelings**. In the last week, have you felt.....

*Have you felt...*

1.	Cheerful? **	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
2.	Worried or anxious?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
3.	That you are enjoying life? **	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
4.	Frustrated?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
5.	Confident? **	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
6.	Full of energy? **	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
7.	Sad?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
8.	Lonely?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
9.	Distressed?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
10.	Lively? **	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
11.	Irritable?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
12.	Fed-up?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>

		lot	bit	little	all
13.	That there are things that you wanted to do but couldn't?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>

Now, I'm going to ask you about **your memory**. In the last week, how worried have you been about...

***How worried have you been about...***

14.	Forgetting things that happened recently?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
15.	Forgetting who people are?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
16.	Forgetting what day it is?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
17.	Your thoughts being muddled?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
18.	Difficulty making decisions?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
19.	Poor concentration?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>

Now, I'm going to ask you about your **everyday life**. In the last week, how worried have you been about....

***How worried have you been about...***

20.	Not having enough money?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
21.	How you get on with people close to you?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
22.	Getting the affection you want?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
23.	People not listening to you?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
24.	Making yourself understood?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>

25.	Getting help when you need it?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
26.	Getting to the toilet in time?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
27.	How you feel in yourself?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
28.	Your health overall?	A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>

We've already talked about lots of things: your feelings, memory and everyday life. Thinking about all of these things in the last week, how would you rate ....

29.	Your quality of life overall? **	Very good <input type="checkbox"/>	Good <input type="checkbox"/>	Fair <input type="checkbox"/>	Poor <input type="checkbox"/>
-----	-------------------------------------	------------------------------------	-------------------------------	-------------------------------	-------------------------------

\*\*items that need to be reversed before scoring

**C. Some questions about things that make life worthwhile (use cue cards)**

[ICECAP]

<p>1. Thinking about love &amp; friendship, which describes you?</p> <p><b>I can have all of the love and friendship that I want</b></p> <p>... a lot of the love and friendship that I want</p> <p>... a little of the love and friendship that I want</p> <p>I cannot have any of the love and friendship that I want</p>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
<p>2. Thinking about the future, which describes you?</p> <p>I can think about the future without any concern</p> <p>... with only a little concern</p> <p>... with some concern</p> <p>... with a lot of concern</p>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

3. Are you able to do things that make you feel valued?

I am able to do all of the things that make me feel valued

... many of the things that make me feel valued

... a few of the things that make me feel valued

I am unable to do any of the things that make me feel valued


4. Thinking about enjoyment and pleasure, which describes you?

I can have all of the enjoyment and pleasure that I want

... a lot of the enjoyment and pleasure that I want

... a little of the enjoyment and pleasure that I want

I cannot have any of the enjoyment and pleasure that I want


5. Thinking about independence, which describes you?

I am able to be completely independent

... independent in many things

... independent in a few things

I am unable to be at all independent


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**This section is to be completed by interview with the patient participant and/or carer on their behalf**

**D. Activities of daily living. Some questions about everyday activities.** Please score what the person has actually done in the last week or so.

**[Barthel index]**

How do they manage with grooming?	Needs help with personal care	0	
	Independent face/hair/teeth/shaving (implements provided)	1	
How do they manage with eating?	Unable	0	
	Needs help cutting, spreading butter etc.	1	
	Independent (food provided in reach)	2	
How do they manage with dressing?	Dependent	0	
	Needs help but can do about half unaided	1	
	Independent (including buttons, zips, laces etc.)	2	
How do they manage with bathing?	Dependent	0	
	Independent (or in shower)	1	
How do they manage using the toilet?	Dependent	0	
	Needs some help but can do something alone	1	
	Independent (on and off, dressing, wiping)	2	
How do they manage with their bladder?	Incontinent or catheterised and unable to manage	0	
	Occasional accident (max once per 24 hours)	1	
	Continent (for over 7 days)	2	
How do they manage with their bowels?	Incontinent (or needs to be given enema)	0	
	Occasional accident (once per week)	1	
	Continent	2	
How do they manage with transferring?	Unable - no sitting balance	0	
	Major help (one or two people, physical) can sit	1	
	Minor help (verbal or physical)	2	
	Independent	3	
How do they manage with mobility?	Immobile	0	
	Wheelchair independent including corners etc.	1	

	Walks with help of one person (verbal or physical)	2	
	Independent (but may use any aid e.g. stick)	3	
How do they manage with stairs?	Unable	0	
	Needs help (verbal, physical, carrying aid)	1	
	Independent up and down	2	

**E. EQ5D quality of life. Some more questions about everyday activities.** Rate as far as possible using information already collected.

**1. Mobility**

Please tick one box

- I am confined to bed.....
- I have some problems in walking about.....
- I have no problems walking about.....

**2. Self care**

Please tick one box

- I am unable to wash or dress myself.....
- I have some problems in washing or dressing.....
- I have no-problems with looking after myself.....

**3. Usual activities (e.g. housework, leisure, family)?**

Please tick one box

- I am unable to perform my usual activities.....
- I have some problems performing my usual activities.....
- I have no problems performing my usual activities.....

**4. Pain / Discomfort: Do you currently have any pain or discomfort?**

Please tick one box

- I have no pain or discomfort.....
- I have moderate pain or discomfort.....
- I have extreme pain or discomfort.....

**5. Anxiety / Depression**

Please tick one box

- I am not anxious or depressed.....
- I am moderately anxious or depressed.....
- I am extremely anxious or depressed.....

**F. Questions about the effect of health problems on everyday life**

I am going to ask some questions about how health problems affect your everyday life.

I want to know about:

- what you do in practice,
- with any kind of help you usually have available,
- compared with other people of your age and background.

[Tick one level for each section, stop when you have identified the right level. If necessary, ask supplementary questions to clarify. A proxy can answer if the subject is unable to do so. In that case 'you' should be read as 'he/ she'. We are interested in 'usual' recent ability, which can be taken as over the last month]



[London Handicap Scale; mobility]

**1. How well are you able to go where you want to go, using any help or means of transport you usually have available? Exclude journeys to hospital.**

Please tick one box

A Can you go everywhere you want to, no matter how far away? Yes, Level 1

.

If no, ask question B

B Do you get out of the house? Yes, Level 2

.

No, Level 3

[Physical independence]

**2. How well are you able to look after yourself? Include things like shopping, housework, cooking, getting to the toilet and getting dressed.**

Please tick one box

A Do you do almost everything to look after yourself that someone like you would be expected to do? You need no more than a little help now and again. Yes, Level 1

.

If no, ask question B

B Do you need help to be available all the time? You cannot be left alone safely. No, Level 2

.

Yes, Level 3

[Occupation].

**3. Next, I am interested in work and leisure activities, which includes any paid work, housework, gardening, visiting people, hobbies, watching TV; anything you do to occupy your time.**

Please tick one box

A Do you do everything you want or need to do, that someone like you would be able to do? Yes, Level 1

.

If no, ask question B

B	Are there are times, when you would like to be occupied, that you do nothing?	No, Level 2	<input type="checkbox"/>
		Yes, Level 3	<input type="checkbox"/>

**[Social integration].**

**4. Next, I want to know if your health stops you getting on with people, including family, friends, and people you might meet during a normal day.**

Please tick one box

A	Do you get on well with people, see everyone you want to see, and meet new people?	Yes, Level 1	<input type="checkbox"/>
	If no, ask question B		
B	Do you find it difficult to get on with people who you don't know well? Maybe you see no-one except close family or the people who look after you.	No, Level 2	<input type="checkbox"/>
		Yes, Level 3	<input type="checkbox"/>

**[Awareness]**

**5. Next, awareness of your surroundings. Assume you are using your usual glasses or hearing aid**

Please tick one box

A	Do you see, hear, speak and think clearly, and have a good memory?	Yes, Level 1	<input type="checkbox"/>
	If no, ask question B		
B	Do you have problems with hearing, speaking, seeing or your memory, which makes life difficult most of the time?	No, Level 2	<input type="checkbox"/>
		Yes, Level 3	<input type="checkbox"/>

**[Economic self sufficiency]**

**6. Finally, affording things you need.**

Please tick one box

A	Can you afford everything you need, including anything you need to buy because of ill-health or disability?	Yes, Level 1	<input type="checkbox"/>
---	---	--------------	--------------------------

If no, ask question B

- B Do you find it difficult to afford your most basic needs? You cannot afford things you need because of ill health. No, Level 2
- Yes, Level 3

### G. Client Service Receipt Inventory

<b>1. Have you been in hospital during the past 6 months? (include index admission)</b>		Yes <input type="checkbox"/>	No <input type="checkbox"/>
If yes, please list the dates and hospital			
<i>Dates</i>		<i>Hospital</i>	
<i>From</i>	<i>To</i>		

<b>2. Have you been in a care home, either for respite or permanent care during the past 6 months?</b>			Yes <input type="checkbox"/>	No <input type="checkbox"/>
If yes, please list the dates, place and whether for respite or permanent care				
<i>Dates</i>		<i>Care Home</i>	<i>Respite / Permanent</i>	
<i>From</i>	<i>To</i>			

**A. PARTICIPANT ACCOMMODATION**

1.	Usual place of residence during the <u>last six months?</u>	Owner occupied house/flat	1
		Privately rented house/flat	2
		House/flat rented from housing associated/local authority	3
	<i>(Also complete Question 3)</i>	Sheltered housing/warden control	4
		Residential home	5
		Nursing home	6
		Acute psychiatric ward	7
		Rehabilitation ward	8
		General medical ward	9
		Other: _____	10

2.	Has ( <i>participant</i> ) lived anywhere else during the <u>last six months?</u>	No	0
		Yes	1
<i>If yes, Accommodation type:</i>		<b>Code</b>	<b>Approximate number of nights spent</b>
1=Owner occupied house/flat			
2=Privately rented house/flat			
3=House/flat rented from housing associated/local authority			
4=Sheltered housing/warden control			
5=Residential home			
6=Nursing home			
7=Other _____			

Only complete if Question 1 is coded 4 to 10			
3 a.	Organisation managing facility	Local authority social services	1
		NHS	2
		Private (for-profit)	3
		Voluntary (non-profit)	4
		Other: _____	5
3 b.	(Participants)'s total contribution to weekly charge for facility		£□□□□□.□□
3 c.	Who contributes towards placement <i>(circle all that apply)</i>	DSS	1
		NHS	2
		Local authority	3
		Voluntary organisation	4
		Participant	5
		Participant's family	6
		Insurance policy	7
		Other: _____	8

## B. PARTICIPANT SERVICE RECEIPT

4a.	<b>Hospital services</b> used over the last six months <i>(include normal accommodation given in Question 1)</i>				
	<b>Service</b>	<b>Name of</b>	<b>Reason for using</b>	<b>Unit of</b>	<b>Total</b>

		<b>ward / clinic / hospital / centre</b>	<b>service</b> <i>(eg nature of illness, regular respite arrangement)</i>	<b>measurement</b>	<b>number of units received</b>
	Day hospital			Day attendance	□ □
	Accident and Emergency			Attendance	□ □
	Outpatient services			Appointment	□ □
	Psychiatric inpatient ward			Inpatient day	□ □
	Other inpatient ward			Inpatient day	□ □
	Other : _____			_____	□ □

4b.	<b>Day services</b> used over the last six months <i>(do not include any day service provided by the accommodation facility in which the participant is currently living)</i>			
	<b>Service</b>	<b>Name of centre/service</b>	<b>Unit of measurement</b>	<b>Total number of units received</b>
	Day care:	Local authority social services department	Days	□ □
	Day care:	Voluntary organisation	Days	□ □
	Lunch club		Visits	□ □

	Social club		Visits	<input type="checkbox"/> <input type="checkbox"/>
	Other : _____		_____	<input type="checkbox"/> <input type="checkbox"/>

4c.	<b>Community – based services</b> used over the last six months								Total number of contacts (Round to nearest whole number)	Average duration of each contact (minutes) (Round to nearest whole number)
	<i>(do not include services provided by people employed directly by the accommodation facility in which the participant is currently living)</i>									
	Service <i>(do not include outpatient services)</i>	Type of visit		Provider agency						
		Domiciliary	Office	Health service	Local authority	Voluntary organisation	Private organisation			
i)	Consultant, non psychiatrist	0		1	2	3	4			
ii)	General practitioner	0	1	1	2	3	4			
iii)	Practice nurse (GP clinic)	0	1	1	2	3	4			
iv)	District Nurse	0	1	1	2	3	4			
v)	Health visitor	0	1	1	2	3	4			
vi)	CPN/CMHN	0	1	1	2	3	4			
vii)	Cardiac nurse	0	1	1	2	3	4			
viii)	Continence nurse	0	1	1	2	3	4			
ix)	Occupational therapist	0	1	1	2	3	4			
x)	Community psychiatrist	0	1	1	2	3	4			

xi)	Psychologist	0	1	1	2	3	4		
xii)	Care manager	0	1	1	2	3	4		
xiii)	Social worker	0	1	1	2	3	4		
xv)	Care assistant	0	1	1	2	3	4		
xvi)	Chiropodist	0	1	1	2	3	4		
xvii)	Sitting scheme	0	1	1	2	3	4		
xviii)	Self-help group	0	1	1	2	3	4		
xix)	Meals on wheels	0	1	1	2	3	4		No of days
xx)	Laundry service	0	1	1	2	3	4		
xxi)	Dentist	0	1	1	2	3	4		
xxii)	Optician	0	1	1	2	3	4		
xxiii)	Counsellor	0	1	1	2	3	4		
xxiv)	Physiotherapist	0	1	1	2	3	4		
xxv)	Other doctor	0	1	1	2	3	4		
<b>Other community-based services:</b>									
xxvi)	_____	0	1	1	2	3	4		
xxvii)	_____	0	1	1	2	3	4		
xxviii)	_____	0	1	1	2	3	4		
xxix)	_____	0	1	1	2	3	4		

## Part Two: Carer Schedule

All the questions below relate only to the last six months.



**C. CARER'S EMPLOYMENT**

5.	Regular employment status <i>(Circle one only)</i>	Paid employment	1
		Retired	2
		Housewife / husband	3
		Unemployed / Student	4
		Full time carer	5
6.	Cut down on paid work in order to provide care for <i>(participant)</i> .  <i>(Also complete Question 7 and 8)</i>	No	0
		Reduced hours	1
		Given up work	2
	By how many hours per week? <i>(Only if reduced hours or given up work)</i>		<input type="text"/> <input type="text"/>
<b>Only complete if in "Paid Employment"</b>			
7.	Most recent occupation type <i>(State main type if more than one)</i>	Manager / administrator	1
		Professional	2
		Associate professional	3
		Clerical worker / Secretary	4
		Skilled labourer	5
		Services / Sales	6
		Factory worker	7
		Other: _____	8
<b>Only complete if in "Paid Employment"</b>			
8.	Total number of paid hours per week <i>(Round to the nearest whole number)</i>		<input type="text"/> <input type="text"/>

#### D. CARER'S ACCOMMODATION

9.	Usual place of residence during the <u>last six months</u> ?	Owner occupied house/flat	1
		Privately rented house/flat	2
		House/flat rented from housing associated/local authority	3
		Sheltered housing/warden control	4
		Residential home	5
		Nursing home	6
		Other: _____	7

#### E. TIME SPENT WITH PARTICIPANT BY PRINCIPAL CARER (*i.e. Informant*)

10a.	Normally live with the participant	No	0
		Yes	1
10b.	<p><b>If No:</b></p> <p>How many hours are spent giving care to the participant each week?</p> <p>(Round to the nearest whole number)</p>	□ □	
10c.	<p><b>If Yes:</b></p> <p>On a typical day, how much of the time can you leave the participant at home alone?</p>	Less than 25% of the time	1
		Between 25% and 49% of the time	2
		Between 50% and 74% of the time	3
		Between 75% and 100% of the time	4

**F. TIME SPENT WITH PARTICIPANT BY OTHER INFORMAL CARERS**

11a.	Do any other people (eg friends and relatives) regularly provide help for the participant	No	0
		Yes	1
11b.	<p><b><i>If Yes:</i></b></p> <p>In an average/typical week, what is the total number of hours these people spend caring for the participant?</p> <p><i>(Round to the nearest whole number)</i></p>	□ □	

12a.	Have any friends or relatives taken time off paid work (over the past three months) to help with care giving?	No	0
		Yes	1
12b.	<p><b><i>If Yes:</i></b></p> <p>Estimate the total number of days taken off work?</p> <p><i>(Round to the nearest whole number)</i></p>	□ □	

**The end - thank you**